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Puerto Rico

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13. ABSTRACT (Maximum 200 Words) Despite evidence in favor of breast cancer screening with mammograms and that screening has increased in the last years, mammogram compliance among low-income, minority and women over 50 years of age has been slow. This three-year project contemplates a study of women's compliance with 1997 NIH screening mammogram guidelines and physicians' observance of NIH guidelines in Puerto Rico. Two-hundred low-income women age 40 to 64 in Puerto Rico will be interviewed to assess factors that affect compliance with screening mammogram in order to determine self-assessment cancer risks. Fifty clinicians will be interviewed to obtain data about mammogram referral patterns. Physicians will be asked permission to examine a random number of records to document referral patterns and select potential survey participants. The first stage of the project was directed to obtain qualitative data to develop the instruments to be administered to the physicians and the women. Focus groups were conducted for this purpose. The women's focus groups served to incorporate pertinent issues and appropriate vocabulary. The physicians' focus group was directed to assess an instrument developed by the research team consisting of case-studies by which to probe if physicians were familiar with 1997 NIH screening mammogram guidelines.			
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MAMMOGRAM COMPLIANCE AMONG LOW- INCOME MIDDLE-AGED WOMEN IN PUERTO RICO

INTRODUCTION

Mammography for low-income and minority women is an important intervention issue as it is still under utilized in these sectors. In 1997, the National Institute of Health (NIH) made public its Consensus Statement regarding breast cancer screening for women age 40-49 and 50-69. The reaction of physicians and low-income women in terms of referrals to screening mammograms and mammogram compliance with the new guidelines still remains to be explored. This study aims to contribute information to this issue. It will look at both sides of compliance with the NIH screening mammogram guidelines for women age 40-49 and 50-64, both for clinicians and the women themselves. How they behave in terms of the guidelines is relevant for screening promotion interventions. The study focuses on compliance with the new guidelines among physicians and low-income middle-aged women in Puerto Rico. This study, originally proposed for five years, contemplated research and a translational experience involving the development of strategies to promote compliance with mammograms by the low-income middle-aged women. However, USAMRMC technical staff and Peer Review Panel recommendations to the original proposal made conducting the translational experience impossible (See Appendix 1). The project agreed upon by all involved parties will focus on the research phase and task and time distribution is as follows:

REVISED STATEMENT OF WORK: 3 YEAR DURATION

TASK 1: SESSIONS WITH FOCUS GROUPS/EXPERIMENTAL DESIGN, months 1 to 12

- Determination of sites for recruitment of samples
- Construct guide for focus groups sessions (for physicians and women)
- Focus groups with low-income middle-aged women (total 4)
- Focus group with clinicians (total one)
- Analysis of results from focus groups sessions (physicians and women)
- Design clinician's interview schedule
- Design forms for data gathering from medical records
- Design and cultural adaptation of survey questionnaire for middle-aged women
- Construct physicians' sampling frame
- Sample selection of physicians
- Questionnaire reproduction (physician's interview)
- Preparation of training for physicians' interviewers and reviewer(s) of medical records
- Training of interviewers
- Training of reviewer(s) of records
- Develop coding and quality control procedures
- Submission of first annual report

TASK 2: INTERVIEWS WITH 50 PHYSICIANS/REVIEW OF 200 MEDICAL RECORDS: Months 13 to 24

Interview of physicians' sample
 Review of medical records
 Data entry and editing
 Incorporate changes resulting from cultural adaptation of survey questionnaire
 Data analysis of physicians' interviews and review of medical records
 Submission of second annual report
 Writing of first set of papers for presentation and/or publication

TASK 3: INTERVIEWS WITH 200 LOW-INCOME MIDDLE-AGED WOMEN: Months 15 to 29

Construct low-income middle-aged women survey's sampling frame
 Conduct sample selection of middle-aged women
 Questionnaire reproduction (women's survey interview schedule)
 Preparation of interviewer's manual and training of interviewers for women's interviews
 Training of interviewers for sample of women
 Develop coding and quality control procedures
 Interview of sample of low-income middle-aged women

TASK 4: DATA ANALYSIS OF SURVEY, Months 25 to 36

Data set up and coding
 Creation of files and programs
 Data entry and editing
 Data analysis
 Write second set of papers for presentation and/or publication (preliminary data on survey)
 Submission of final project report

BACKGROUND

Despite the powerful scientific evidence in favor of breast cancer screening with mammograms and that screening has increased during the last five years, research indicate that mammogram compliance among specific sectors such as low-income, minority women, and women over 50 years of age has been slow (Rakowski et al. 1993; Rimer 1995). Many health professionals assume that if a practice has been demonstrated to be beneficial (i.e., early detection reduces cancer mortality), the general population will logically accept it and will practice it. Nonetheless, knowledge of the consequences of a behavior is not necessarily a deterrent of a specific conduct. Even though empowerment starts with knowledge, other factors are equally important to cause change and motivate action. Certain factors have been related to screening mammogram utilization among women in the U.S., but none is more important than a physician's recommendation or referral (Dawson & Thompson 1990). Other predictors include knowledge of the

guidelines, belief in the potential curability of cancer or that screening is worthwhile, higher socioeconomic status, non-minority status, and age below 50 (Champion 1994, Lacey 1993, NIH 1990, Rimer et al. 1989, Urban et al. 1994, Vernon et al. 1990, Zapka et al. 1993).

A survey of women age 65 and older conducted in Puerto Rico found that the primary reason for mammography compliance was a physician's referral (Sánchez-Ayéndez et al. 1997). Statistical analysis demonstrated that external factors were more significant than personal ones in terms of compliance with early detection of cancer behaviors. The analyses determined that the most significant factors for undergoing a mammogram in the two years previous to the interview were related to the health care provider: having a referral from a physician, having received information from a health care provider about breast cancer and early detection after menopause, and having visited a gynecologist. Logistic regression analysis determined that the most significant factor was a referral from a physician.

There has been an increase in the number of women who have received regular screening for breast cancer, yet specific sectors are not being screened. Access to mammograms is a problem for minority, low-income women, and women over 50. Hispanic women's utilization of clinical breast exam (CBE) and mammogram are lower than that of their White and Afro American counterparts. The report "Healthy People 2000" indicated that in 1987, only 20% of Hispanic women age 40 or older in the U.S. had ever received a CBE or mammogram and set the objective to increase to 80% by the year 2000 the total for Hispanic women age 40 or older who undergo breast cancer tests. There is also a difference in utilization of mammograms for screening between women of lower socioeconomic strata and those in upper levels. Barriers revolve around access, cost and education. There is a need for research focusing on compliance predictors for breast cancer screening in middle-aged women, particularly minorities and low-income women, as well as on factors that affect a clinician's response to follow the NIH¹ screening mammogram guidelines for women age 40 to 49 and 50 to 64.

For those involved in breast cancer health promotion, it is essential to address how the needs of low-income and minority women are being met in order to comply with the screening guidelines. Most research has focused on barriers to services. Research has stressed that a main factor, if not the principal one, affecting mammogram compliance is lack of referral from a health care provider. In Puerto Rico, women cannot undergo a screening mammogram without a referral from a physician. Therefore, it becomes imperative to understand which factors affect physicians' compliance with established guidelines when recommending a screening mammogram and which factors affect a woman's decision, after she has received a referral, to undergo a mammogram. What factors do clinicians consider when recommending screening mammograms to women age 40 to 49 and 50 to 64? What variables are better predictors that a woman will have a

¹ 1997 NIH Consensus Guidelines

mammogram once she receives a referral? How does a woman's self-assessment of breast cancer risks affect screening mammogram compliance? The answers to these questions stem from behavioral and socio-cultural factors and must be considered when addressing the needs for services among low-income and minority women. Both sides of the issue, women and clinicians, must be investigated.

Mammography for low-income and minority women is an important intervention issue. During the last two years, the debate relating to breast cancer screening guidelines, specifically mammograms, has been the center of controversies ever since NIH made public its Consensus Statement regarding breast cancer screening for women age 40 to 49 and 50 to 69 (NIH Consensus, 1997). Guidelines indicate that the data currently available does not warrant a universal recommendation for mammography for all women in their forties. Each woman should decide for herself whether to undergo mammography. Her decision may be based not only on an objective analysis of the scientific evidence and the consideration of her individual medical history, but also on how she perceives and weighs each potential risk and benefit, the values she places on each, and how she deals with uncertainty. For women over 50, the 1997 policy states they should undergo mammograms every one to two years beginning at age 50 (Christensen, 1997). The reaction of physicians and low-income and minority women in terms of compliance with the new guidelines and referrals to screening mammograms remains to be explored. The proposed project will focus on compliance with the 1997 guidelines by physicians and low-income middle-aged women (age 40 to 64) in Puerto Rico.

RESEARCH QUESTIONS AND METHODS

Research questions for the duration of the three year project are the following:

1. Are physicians adhering to the recommended NIH screening mammogram guidelines for women age 40 to 49 and 50 to 64?
2. How does a woman's self-assessment of breast cancer risk affects compliance with a screening mammogram referral?

This investigation aims to understand which variables are better predictors of screening mammogram compliance among low-income middle-aged women in Puerto Rico, once they have received a physician's referral and which factors could be affecting physicians' compliance with current NIH screening mammography guidelines.

The research methods that will be used are focus groups, individual interviews, and examination of medical records. Focus groups were conducted to gain insight to breast cancer and screening knowledge and attitudes, screening practices, and barriers to screening mammograms of low-income women age 40 to 64. With the information obtained from the focus groups, a culturally and socially sensitive questionnaire was developed and will be administered to a sample of 200 low-income middle-aged women in two sites in Puerto Rico during the second year of the project. A focus group was also

conducted to obtain feedback from physicians for a questionnaire developed to probe into clinicians' knowledge of current guidelines for the age groups under consideration. Interviews comprised of hypothetical case studies and open-ended questions will be conducted with physicians to obtain information on practices pertaining to new screening guidelines and attitudes toward the patient-physician relationship. Physicians will be asked permission to examine a random number of records (300 total) to document referrals to screening mammograms and to associate referrals to women's breast cancer risk factors and physician's attitude toward the client-health provider relationship. Record examination will also be helpful in determining if 1997 NIH breast screening guidelines are being followed for women age 40 to 49 and 50 to 64.

Potential female survey participants will be recruited from women whose records are examined who are age 40 to 64 and who have received referrals for screening mammograms since January 1998. A random sample of 200 low-income women who meet both criteria will be selected. Research variables include sociodemographic characteristics, health history, knowledge and attitudes toward breast cancer and mammography, access to services, perception of patient-physician relationship, and knowledge of available services for mammograms.

OBJECTIVES

Understanding how a woman's self-risk assessment affects her decision to undergo a screening mammogram, once barriers such as access to medical services and a physician's referral are overcome, is an essential step in designing interventions (Jack et al. 1993, Lacey 1993, Rimer 1995) and one that is not often studied. Dolan (1995) found that among women who do receive recommendation for a screening mammogram, low-income women are among those least likely to undergo the procedure. The answers to the proposed research questions will be helpful to develop recommendations to assess screening and risk factor control and to design interventions for low-income middle-aged women.

The proposed project contemplates a qualitative and quantitative study of women's compliance with current screening mammogram guidelines and physicians' observance of recommended screening guidelines for women in the age 40 to 49 and 50 to 64. It will center upon interviews to determine which variables are better predictors of compliance with screening mammograms among middle-aged (age 40 to 64) low-income women in Puerto Rico and which factors affect a physician's decision to recommend a screening mammogram according to the differences established by the 1997 NIH guidelines. The emphasis of breast cancer screening campaigns is geared toward motivating women to have a mammogram. But in Puerto Rico, as in many other countries, this procedure requires a referral from a physician. Campaigns are designed to improve knowledge that mammograms can save lives. Do we need to "equally" educate those in a position of recommending that a woman undergo a screening mammogram? The objectives of the three-year project, as stated in the original proposal, are the following:

1. To obtain qualitative data about personal and external factors that affect compliance with mammogram screening that will be used in the design of a culturally-sensitive survey questionnaire.
2. To obtain qualitative and quantitative data about factors that explain screening mammogram referral patterns among physicians.
3. To obtain quantitative data about factors that affect compliance with screening mammogram in order to determine the importance for low-income middle-aged Puerto Rican women's self-assessment of breast cancer risks.

RESEARCH METHODS

Focus Groups

Introduction

The first stage of the study was directed toward the search of qualitative data to develop the instruments that would be used for both the interviews with physicians and the survey of low-income, middle aged women. The method of investigation that corresponds to this stage was focus groups. This technique was used in order to obtain qualitative data about the factors that predict screening mammograms compliance among low-income women age 40 to 64, once they have a referral from a physician. This method was also used to examine the factors that affect the compliance of primary physicians with the 1997 NIH recommended screening mammogram guidelines for women age 40 to 64.

Focus or interest groups are a qualitative investigation technique that are used to examine the socio-cultural characteristics and psychological processes that determine people's conduct. Focus groups explore ideas and opinions about a specific topic (Basch 1987, Krueger 1994) that help to clarify important research variables and facilitate the formulation of hypotheses that can be verified by a greater number of subjects.

I. Focus Groups of Women age 40 to 64

The investigative strategy of the focus groups was carried out with the main purpose of gathering information about the factors that can affect screening mammogram compliance among low-income women age 40-64 after having received a referral from a physician. With this technique, this study could obtain data about the following aspects: knowledge and attitudes regarding breast cancer and screening mammogram; data about the information provided by physicians during patient visits; perceptions about doctor-patient relationships; tests for breast cancer screening done by or recommended by physicians, particularly mammograms; knowledge about existing mammography services; and barriers to having mammograms.

The results of the analysis of the focus groups were used to design a socially and culturally sensitive questionnaire that would evaluate the factors that affect screening

mammogram compliance for women in the low-income, middle-aged population. As part of the analysis, appropriate vocabulary was also evaluated in order to adapt the questionnaire. This instrument was tested on ten low-income women age 40-64 to evaluate how they responded to cultural and social sensitive issues, vocabulary, and sequence of questions. The questionnaire will be administered to a survey of 200 Puerto Rican women age 40-64 who have received a referral from a physician for a screening mammogram. The women will be clients of one of two different health centers in Puerto Rico in the metropolitan and non-metropolitan area.

II. Physician's Focus Group

The main objective of the physician's focus group was to discuss the topics that would be emphasized in the interviews carried out with a group of physicians from the two selected areas, metropolitan and non-metropolitan. The physician's questionnaire will be administered to a total sample of 50 doctors.

Selection of Focus Groups

Two geographic areas (metropolitan and non-metropolitan) were selected for the women's focus groups. In the metropolitan area, the women were recruited from a health center located in the inner-city.² The center selected for the non-metropolitan area was located on the northeast coast of Puerto Rico. Both centers were also used to recruit the sample of medical records and the 200 women who will be interviewed. As well as collaborating with the selection of focus-group participants, these centers provided the physical facilities for carrying out the group discussions.

A total of five focus groups were held (four women's and one physician's focus group) with a maximum of seven (7) persons in each group. The eligibility criteria for the women's focus groups were the following:

- women age 40 to 64
- low socioeconomic level
- voluntary participation
- user of health center services

The physicians were recruited using the technique of "snow-balling". The eligibility criteria for the physician's focus group were the following:

- primary physician
- voluntary participation

² The names of the centers are not mentioned in order to maintain confidentiality.

The women's focus groups were divided by geographic regions and within each region the sessions were divided by age: women age 40 to 49 and women age 50 to 64. The final composition of the focus groups were the following:

- one group of women age 40-49 from the metropolitan area
- one group of women age 50-64 from the metropolitan area
- one group of women age 40-49 from the non-metropolitan area
- one group of women age 50-64 from the non-metropolitan area

The focus group of physicians was formed from health centers with specialties in gynecology, family and internal medicine.

The objective and methodology for this study was explained to the directors of the health centers, who accepted to cooperate with the research team. Recruitment was carried out in cooperation with the head nurses from the centers. The women who agreed to participate in the study received follow-up telephone calls. Participants were also recruited in the health center the day of the session in order to meet the minimum required number of participants.

The different health centers were visited prior to each session in order to select an adequate site to guarantee little or no interruptions of the sessions, continuity during the process, and adequate social interaction. The physician's focus group session was carried out in a private room in a restaurant in order to guarantee all of the above mentioned considerations.

The women's focus groups were carried out during the month of December and the physician's session was carried out during March, with schedules that were appropriate for all of the participants. The participants were seated at a rectangular table to facilitate visual eye contact between the participants and the moderator. In addition to the moderator, an observer and a note-taker were present at all of the sessions. Open-ended questions were used to promote dialogue; the sessions were tape recorded with the consent of all participants. The research team designated a note-taker who was in charge of noting pertinent observations as well as non-verbal communication. The observer was in charge of noting the main topics that arose from the discussion. Notes were later compared to the taped conversation. The sessions lasted approximately 60 to 75 minutes each.

At the beginning of both the women's and the physician's sessions, the members of the research team introduced themselves and explained the objectives of the project. The participants then introduced themselves. For the women's sessions, a consent form was read aloud and explained after the self-introductions. After signing the consent form, each participant was given a copy of the form. During the group discussion, the moderator intervened to stimulate and clarify responses about the topics of interest. A brief socioeconomic profile of the participants was also completed after the discussion. The

physicians read the consent forms and questions were clarified. A brief profile was also completed about the health providers and women.

Description of Health Centers

Two regions were selected to carry out the investigation: a large metropolitan inner-city area and a coastal non-metropolitan area. The different regions were used in order to shed light on factors that could affect mammogram compliance among low-income middle aged women.

I. Metropolitan Inner City Community Health Center

The metropolitan region health center offers primary health services to five low-income communities, including patients covered by Medicaid, Medicare, private health insurance and other types of payment. This health center operates with both federal and municipal funds. It has a Board comprised of health services users, residents of the community, and representatives from the municipal area where the center is located.

The health services offered by the center are directed at the following: prevention; maintenance of integrated patient and family health; detection and early treatment of diseases and health conditions; and management and adequate control of chronic conditions through primary health care.

This center offers the following services:

1. Primary medical and preventive health services with coordination of a primary physician, including
 - a. Healthy child and adult care, prenatal care, family planning, testing for early cancer detection, and vaccinations.
 - b. Specialized services
 - Pediatrics, Internal Medicine, Gynecology and Obstetrics, Surgery and Urology.
2. Complete primary and prosthetic dental services
3. Mental Health Services
4. 24-hour Emergency Room, seven days a week
5. Ambulance transportation
6. Pharmacy
7. Clinical Laboratories

8. Radiology (X-rays)
9. Nutrition evaluations and counseling
10. Health Education
11. Social Work
12. Respiratory Therapy
13. EKG (electrocardiograms)
14. Health Certificates
15. WIC (Women Infant Child)

The collaborators and facilitators of the study's focus groups in this center were the Executive Director, the Medical Director, the Gynecological Nurse, the Social Workers and the Health Educator.

II. Non-Metropolitan Community Health Center on Northeast Coast

This Community Health Center is organized for the complete care of area residents. It has a Board of Directors comprised of citizens organized in a non-profit corporation in accordance with the laws of Puerto Rico and under Section 330 of the Federal Public Health Law. The mission of this center is to provide high quality services and to help the patients that choose this primary care center to adopt healthy life styles, maintain their health, and to improve health that is affected by an illness.

The services offered by this center are the following:

1. Primary medical services and health prevention under the coordination of a primary care physician:
 - a. Healthy child and adult care, prenatal care, family planning, tests for the early detection of cancer and vaccinations.
 - b. Specialist services
 - Pediatrics, Internal Medicine, Gynecology and Obstetrics, Surgery and Urology.
2. Referrals for other specialized services
3. Hospitalization and sub-specialists services
4. Complete primary and prosthetic dental care

5. Ophthalmology and Dermatology
6. Mental Health Services
7. 24-hour Emergency Room
8. Ambulance transportation
9. Pharmacy
10. Complete laboratory clinics
11. Pathological Laboratory by referral
12. X-rays (all days)
13. Nutrition evaluations and counseling
14. Health Education
15. Social Work (coordination, orientation and assistance to obtain services covered by insurance and that are not offered in these facilities).
16. Respiratory Therapy
17. EKG (Electrocardiogram)
18. Health certificates
19. WIC (Women Infant Child)
20. Demographic Register

The collaborators and facilitators of the study's focus groups in this center were the Medical Director, the Nursing Supervisor, and the Clinic Operations Manager.

RESULTS

Focus Groups: Middle Aged Women

Procedures

The discussions for the women's focus groups were organized according to the following objectives:

1. To obtain qualitative data about the knowledge of breast cancer for low-income, middle aged women in Puerto Rico.
2. To obtain qualitative data about personal and external factors that affect compliance with mammogram screening.
3. To become familiar with the vocabulary used by low-income, middle-aged women in Puerto Rico when referring to their experiences with early detection for breast cancer procedures and health-seeking behaviors.

The analysis of the focus group discussions was centered around the following guide questions:

1. Breast cancer:
 - Should any of you be concerned about cancer?
 - Should you be concerned about breast cancer?
 - Who do you think about when we talk about breast cancer?
 - How can we know if someone has breast cancer?
2. Mammograms
 - What is the first thing that comes to your mind when I say the word mammogram?
 - How does it make you feel?
 - How many times should a woman have a mammogram? Is one time sufficient?
 - How many times?
 - What does a woman have to do to have a mammogram?
 - When is it no longer necessary to have a mammogram?
 - a. For women who have had a mammogram:
 - Why did you have a mammogram?
 - Can you tell us a little about your experience having a mammogram?
 - Can you remember what you were told before having your first mammogram?

- Was there anything about this experience that would make you think twice before having another mammogram?
- Have you ever recommended to another woman that she should have a mammogram? What did you tell her? Did she have one? Why not?

b. For women who have not had a mammogram:

- Has a doctor ever suggested or recommended that you have a mammogram?
- What reasons could a woman have for not having a mammogram?
- Is there anything that we haven't talked about that would be important to say about this topic?
- Do you have any suggestions for our study?

The discussions from the focus groups were transcribed from tape recordings and corroborated with the notes from the note-taker and the observer. A transcription sheet was developed to compile and analyze the information. The information from each question was divided into three columns: transcription, vocabulary and analysis.

Results: Focus Group Sessions

I. Characteristics of the Participants

A total of 24 women participated in the focus groups. Of these women, 11 were from the metropolitan area and 13 were from the non-metropolitan area. There were 45.8% of the women age 40 to 49 and 54.2% in the age group 50 to 64. In the metropolitan area, 54.6% of the women were age 50 to 64 and in the non-metropolitan area, 53.85% were in this age group. The last grade of study was distributed between fourth grade and last year of high school; two participants had completed a higher academic level. Of the 24 participants, 63% had not completed high school, 29% had completed high school, and 8% indicated that they had a higher academic level.

Fifty percent of the participants were either married or living with a partner; 21.5% of the participants indicated that they were divorced or separated. There were 91.3% of the women who said that they practiced some type of religion and of this group, 60% indicated catholicism. Of the total number of participants, 75.8% said that they have had a mammogram at least once. Of this group, 56% were participants from the non-metropolitan area. The women indicated that they have had mammograms between 1987 and 1999. Sixty percent of the participants indicated that they had a mammogram during the previous year. Of the women participating in the focus groups, 67% of those who had a mammogram were in the age 50 to 64 group. A large majority of the women, 87.5%, indicated that they were not currently working.

II. Vocabulary Used in the Focus Groups

No differences were observed regarding the vocabulary used by the participants when talking about breast cancer in either age groups or health centers. This finding is consistent with the study by Sánchez-Ayéndez et al. (1996) about beliefs and knowledge about breast cancer for women age 65 and older in Puerto Rico. This study made the following observation:

It was observed that none of the participants, even those professionals who were physicians or worked as volunteers at the Puerto Rico Cancer Society, employed the scientific term for breast cancer in Spanish. In Spanish, the scientific term for breast cancer is "cáncer de mama". The participants utilized "cáncer del seno", which is the widely used term in Puerto Rico and most Spanish-speaking countries. This is culturally related. Breast-feeding is a function of the breast and in Spanish, breast-feed is "amamantar" or "darle al bebé de mamar". At the same time, the breast has a sexual function. In a cultural tradition where a strict dichotomy exists between a woman's maternal³ and sexual roles, a distinction is made between both functions of the breast and a more euphemistic terminology is used to establish a compromise between both spheres of female activity.

Different terms were used for breasts, including breast, bosom, and teats ("seno, mama and tetas"). One participant mentioned that the correct terms for breasts aren't used even when young girls begin to develop, breasts were called "little stumps" ("toconcitos") or "teaties" ("tetis"), but the word breast isn't used, which was one reason why women were not aware of breast disease:

"The problem is one of education, that is, the root of all of women's situations and problems is one of education, what the focus is for me to understand my body before my breasts start developing and how I am taught. That is, we didn't talk about the teaties or the little stumps, as they were called..."

In terms of the symptoms or effects of breast cancer, the participants used the following vocabulary when referring to nodules:

- cysts or little cysts
- little balls, balls or lumps
- little masses, little masses of cysts
- malignant or benign gland
- granule or little pimple

³ "Marianismo" (devotion to the Virgin Mary) is still prevalent in Puerto Rico and other Spanish-speaking countries.

A few participants, but very few, used the term nodule. Reference was also made to pre-nodule symptoms such as:

- hardening
- swelling
- pain
- discomfort

Sometimes the participants recognized the concept of metastasis and they referred to this as "cancer spreading throughout the body" or used a similar term, "*metastasia*". One participant said that if the cyst wasn't removed from the roots it could come back and grow again. Some women mentioned other diseases related to the breasts such as mastitis, fibrosis, or "fibrocystic".

The participants also used certain terms for early detection tests. They mentioned "feeling the breast" for self-exams and "the exam that the doctor performs" for a clinical exam. Regarding mammography, few women used this term, but it was used more frequently than the term nodule. The terms that were commonly used were the following:

- breast exam
- breast x-ray
- breast test

Regarding the procedure, participants mentioned "squashing the breast", "squeezing you", and "getting squeezed".

The participants also made references to other tests related to the detection of breast cancer. They used the words sonomammogram and biopsy. One participant mentioned that before an "operation" (biopsy), "they located the bump with a wire".

For the procedures used once the disease has been diagnosed, the participants did not use the term mastectomy. The following expressions were used when referring to this surgical procedure:

- remove or amputate the breast
- breast extraction
- radical removal
- body mutilation

The participants also mentioned specific treatments; they specifically used the term chemotherapy. One of the participants used the phrase "burn the cancerous cells" instead of radiation.

III. Knowledge about Breast Cancer

A. Definition of cancer.

1. Definition:

The participants perceive cancer as a cell disorder. The following statement illustrates their vision of the disease:

"Cancer is a cell disorder; that is, the cells divide and multiply. In medical terms, the cells divide."

2. Risk Factors/Protection:

The participants mentioned various risk factors that can be classified in the following main categories: blows or injuries to the breast, family history and personal circumstances.

There were comments by some women who believed that blows to the breast or tightly constraining the breasts increases the risk of breast cancer. One woman expressed the following:

"...this holds back a person's blood circulation and could cause something bad to happen, because cancer could come from any blow that you get, the blood coagulates and the coagulated blood just stays there..."

Other women mentioned that tight bras could cause breast cancer.

The personal circumstances that were mentioned included having children, breast-feeding, hysterectomies, smoking cigarettes and the use of hormones. Regarding the latter, one woman commented:

"It's recommended, they always say that after age 40, supposedly every women, and especially women who don't have uteruses, like in my case where I don't have a uterus or ovaries, well, I've been taking hormones since I was 38 years old, because it's recommended, because it doesn't go so well for all women. There's a percentage, not very high, maybe 5% of the women who take hormones, who tend to get little lumps and things in the breasts and due to this, the doctors recommend that once a year they have a mammogram."

Having children and breast-feeding are seen as protective factors from the risk of contracting the disease. One woman commented the following:

"The doctor said that it's not necessary and if he doesn't give me the referral, I go to a different one... I have 12 children and I think that I breast fed so much that I'm never going to get breast cancer..."

Moderator: "Did you breast feed your 12 children?"

"All 12 of them, so, I'm not going to get breast cancer."

The women expressed their convictions that there is a relationship between smoking and breast cancer. Regardless that this is an incorrect perception, this was one of the risk factors mentioned in the focus group sessions.

Some of the participants also stated that if a female relative had suffered from cancer; a woman had a higher chance of developing breast cancer. However, no differences were mentioned for maternal and paternal relatives.

B. Symptoms: pain, secretion, nodules

During the discussions, the elements of detection and the relationship to pain, as well as the consequences that can be caused by the disease were brought up. In terms of pain, three participants expressed the following:

"They say that cancer doesn't hurt."

"What happens is that when there's pain and discomfort it's because it's already spread throughout the body."

They say that at first, cancer doesn't hurt, but if it's in the last stages, and it's spread all over the place, it's so painful that you can't bear it, that's what they tell me."

The participants also perceived that there are certain arguments that can get entwined to create barriers so that women refuse to comply with mammogram referrals. The following expressions show suspicion in regards to pain, symptoms, and the disease according to the experiences of other women and to more and less evident knowledge:

OK, I've recommended [mammograms] to my friends because sometimes they tell me about the discomfort that they feel in their breasts and I tell them, you should go have the test because sometimes you don't know what there is. Because listen, this happened to me and when I felt this [pain] I went running right to the doctor and look what they found so they had to operate on me. God knows if I hadn't gone to the doctor I would still have that here and now I would have cancer throughout my body, leaving my children orphans. That's the recommendation that I tell them."

"You can have the mammogram, but you're more motivated if you feel a pain like I felt when I laid on my side. I was uncomfortable when I laid face down and I said

to myself, goodness, what is it that I feel? What's wrong with me? And one day I came here and I told the doctor what I felt. I got an appointment and I told him what I was feeling; he gave me a referral right away and when I had the mammogram, they found this and I continued treatment and when it was time for an operation they sent me to the Medical Center to have the operation. They took out three cysts, this was a mass that could have turned into cancer."

Some of the comments appear to be contradictory regarding this aspect, but they also are a basis for understanding the above mentioned perceptions:

"My situation was, I had something, but I didn't like to go any place about this, and I still don't. Well, I squeezed myself during my menstrual cycle and when I squeezed [the breast] I saw this brown liquid and I said "Oh no, I have cancer!". To me, it was blood so then, I went to the doctor and I told him what was going on and then he said to me: You have never had [a mammogram]?"

C. Early Detection Tests

The participants mentioned clinical breast exams, self-exams and mammography as tests for detecting cancer. In terms of the clinical exam, women discretely, but explicitly used this expression:

"...the doctor touches me..."

The women also indicated that mammography was a clinical exam for detecting breast cancer:

"It's a study of the breasts that's recommended for us to do I think at least twice a year. It's a study that will detect if there is a malignant or benign gland or any deformity or if there is something in the breasts."

The women implicitly mentioned that there are studies to detect breast cancer:

"There's a way of knowing it from the studies and also from the symptoms."

The participants also mentioned the breast self-exam as a method of detection:

"And also palpating ourselves"

In both centers used for the focus groups, the women recognized that mammography is the best method for detecting breast cancer. The participants explicitly said this in the following statements:

"...But one should have a mammogram because it's very important. It's the only way that one can know if there is something, if it's going to reproduce, God forbid, or if it is something that they can investigate and check out because finding out things in time has a solution..."

"Well, with mammography they can detect the breast cancer and if it is just starting, we have the chance that they can help us and cure us or make us better for an indefinite length of time."

"Not with the hand, because it's better with mammography. Because with mammography you have a better chance to know everything that you have inside and they can see you, but with the hand it's not valid."

Other less explicit comments were the following:

"...the mammography doesn't prevent but it helps because if we don't have a mammography, how are we going to know if we have [cancer] or don't, because a doctor told me this and they have also told me, "look, breast cancer..."

"The general doctor gives one every year, at least for me, he sends me to have a complete evaluation, everything, everything, and with all of these evaluations, including kidneys, urine and sugar and heart and all this, they include the Pap and the mammography..."

"It doesn't prevent, it [mammography] detects."

There were also participants who doubted the benefits of mammography:

"I heard that one time there was a woman who had a mammography but they didn't check under the armpit and that was where she had the cancer and she died anyway, afterwards they realized that it was underneath."

Some participants also recognized that there are exams better than mammography for early detection:

"...No; I had my first mammography and apparently they saw something so he [the doctor], to be surer, sent me to do a sonogram..."

IV. Mammography

A. Knowledge

The knowledge that the participants expressed about mammography were related to its usefulness, frequency and base age to have the exam.

1. Usefulness or objective

The following excerpts demonstrate the participants's implicit understanding of the usefulness of mammography:

"No, no, I like it. You have to have one [a mammography] because you never know."

"...you have to be checking yourself...I had something in the mammography and as was said, she [the doctor] sent me to have a sonogram..."

"I'd say more or less...if a person knows that at what age one should have a mammography, then one should go because, it's one thing for blood tests to know about a lot of diseases that one might have, but one doesn't know if one has breast cancer from a blood test, same as the vaginal. I don't think that anything about the breast comes from blood tests."

Others indicated the need to have a mammography because of the objective of detection:

"In the community centers, in gynecology, the Medical Center, in this center, in the schools, for the girls, they are teaching since very young that is has to be done [referring to mammography]."

"No, no, I am nearly convinced because I know that I have to have one...because...one has to make time for this..."

Some participants knew about factors that protected from the disease but still considered that having a mammography was an important need:

"The doctor tells me that it's not necessary and if he doesn't give it to me [the referral for a mammography] I go to a different doctor. It's that...I have 12 children and I think that I breast fed so much that I am never going to get it [breast cancer]..."

2. Frequency

The participants showed less uniformity in terms of knowledge about the frequency with which one should have a mammography:

"Every year."

"What is recommended for a person who is healthy is once a year, if they detect something, I think it's every six months."

"That is, if a person doesn't have any problems, it can be annual and if the person has a problem, it should be more often."

It's a study of the breasts that's recommended for us to have I think at least twice a year, and it's the study that's going to detect if there's a malignant or benign gland or any deformity or something in the breasts."

"Well, for me [...] they told me that it was every two years, because it's been a little over a year for me since they did my mammography and they told me that now it's every two years."

"I'm not worried about anything, since I try to take care of myself for diabetes, mammography I do annually."

3. Age

The expressions regarding the age at which one should begin having mammographies were even more disperse and reflect a lack of knowledge about NIH guidelines:

"I found out that it's when you reach 50 years old."

"...and for a while now I've heard that it's already when you're 40 and over and that any girl, any young person is susceptible [...] but you know, I have a niece who's 24 years old, so in our family there's cancer."

"Well, I've always been told that it's 35 and over. From 35 to 40."

"I've heard on television, on the news, and there's a health section sponsored by [...] Pharmacies and there I've heard that women 40 years old or 50 and over should have an annual mammography."

"Well, I would say that it would be better early like when one's reaching 40, who knows what you have over all this time, it's better earlier."

"From 25 to 30 should already check oneself out because later, 10 years later, one doesn't know what there is, so earlier I would say is much better because you can detect anything on time."

"...since you're 40 and you've got to start, because even though you feel young, things aren't the same anymore."

"At 40."

Moderator: "What have you heard about when is the first time that one should have a mammography?"

"When there's discomfort"

"At 40"

"At 35"

B. Perception of mammography

The participants expressed that a mammography hurts or squeezes the breasts. The comments varied from a little to a lot of pain, as shown in the following expressions:

"No, mammography, no; it hurts a little because they squeeze, it hurts. They say that now there are some machines that don't have to press so much, is that true?"

"Because they told me that the mammography squeezed and for me, when I was about 25 years old, I had some glands and they operated on me and took them out. Well, I was afraid of it, because they told me that it squeezed and they were going to press a lot but I had one and really, it didn't hurt. I had it because I fell and I hit myself [in the breasts] and then it hurt and I had it and I had something in the mammography and...they sent me to have a sonogram."

It hurt me [the mammography] in my opinion and more when they compressed me. Like I said, I'm not going to go back and have one of those things. I think that they'd have to arrest me."

"And they took me and made me go this way and that way and it squeezes [the mammography] and when they put me like a waffle maker I said...because you know, they pressed and irritated, for me it was uncomfortable and I'm going to say that I ended up hurting more. I had a bad experience."

"You know, I had pain in my breast for about a week. I could hardly put on my bra and I had to leave them [the breasts] loose."

C. Attitudes that motivate participants to have a mammogram.

In addition to the usefulness of mammography, pain was mentioned as a motivation to have early detection exams. Symptoms such as pain do not always act as a barrier, but rather help to form an attitude that results in compliance with a referral and makes a woman seek a referral.

"You can have the mammogram, but you're more motivated if you feel a pain like I felt when I laid on my side. I was uncomfortable when I laid face down and I said to myself, goodness, what is it that I feel? What's wrong with me? And one day I came here and I told the doctor what I felt. I got an appointment and I told him what I was feeling; he

gave me a referral right away and when I had the mammogram, they found this and I continued treatment and when it was time for an operation they sent me to the Medical Center to have the operation. They took out three cysts, this was a mass that could have turned into cancer."

V. Barriers

The reasons expressed by the women as barriers to having mammography were divided between personal barriers and system or external barriers. The analysis of the barriers revealed similar results in the different focus groups.

A. Personal Barriers

Apprehensions about the discomfort caused by the mammography procedure and fear of a diagnostic of cancer were the most evident attitudes identified as personal barriers. The participants expressed their fears and apprehensions of mammography per se:

1. Apprehensions

"Sometimes we're afraid to have the exams, not only mammography but the Papanicolaou, because there are so many myths and it makes one a little scared. I had the experience with an aunt who, coincidentally, died of breast cancer. Right now I have a friend that felt a little discomfort in this breast and had the test and has some little lumps. As a matter of fact, she had to get part of the breast opened up here to extirpate right away, they're giving her chemotherapy and she's frustrated because she had to leave her work."

The pain caused by the procedure was also mentioned:

"Because they told me that the mammography squeezed and for me, when I was about 25 years old, some glands came out and they operated on me and took them out. Well, I was afraid of it, because they told me that it squeezed and they were going to press a lot but I had one and really, it didn't hurt."

"Being afraid [of mammography] but finally I decided to go."

"For fear [of mammography]."

For other women, the discomfort and the pain that results from mammography can inhibit repeating the procedure in the future:

"In fact, it inhibited me a lot [the pain/discomfort] to go back for a second [mammography]."

No one mentioned fear of the radiation as an inhibitor for compliance with a referral.

2. Fears

In some instances, the fear of the participants to have a mammography was expressed in terms of fear of the diagnostic of cancer. The following expressions exemplified these feelings:

"I felt fearful because, it was that I had never had one and then when you have the test, the employee treats you well, she puts you in the machine, but afterwards you keep thinking, how did it come out? But it makes one tense to have it."

"To have it and wait for the results because you're a little afraid about when you go to your doctor and he tells you that you had the test and looks at the results and he tells you that here you have this and what you have to do; you panic and it's not easy, because as brave as you might be, if you have a disease..."

"Because she says that she's afraid, if something shows up. I'll tell you that you're still in time, you have three children and if I'm sick, and you with your three kids, if it's not me, it's you. Who's going to take care of them? You have to take care of yourself to take care of your children. Because I adore my children and my grandchildren but if I don't take care of myself, how am I going to take care of them and I always tell them that the "mom" is the trunk for her children and you know that fathers, there are few fathers who are responsible for their children. My best friend, she's one who never goes to the doctor and she's 50 years old and has never had a mammography or a Papanicolaou, nothing."

3. Modesty

Some women commented that exposing the body and having to touch their breast could be uncomfortable due to their modesty and shyness and this becomes a barrier. Some examples are the following:

"...Because one's health is first, one has to, even if one feels shy, but if it's for one's health, and at that moment it's nothing else, and sometimes afterwards, one doesn't even see the faces of these doctors ever again."

"Because of shyness".

B. System or External Barriers

The main system barriers that obstruct the maximum utilization of mammography as a strategy for early detection of breast cancer were the following: economic factors,

transportation, and aspects related to the relationship between the health professional and the patient.

1. Cost of procedure and access to financing

The economic barriers that lessen the use of mammogram referrals appear to vary among health centers. In one of the centers, the reimbursement at this time for the exam can be \$35.00 to \$40.00 while in the other center, the interviewees reported that the reimbursement for mammography was \$.55 to \$3.00 if the patient has the CESCA insurance card.⁴

The participants from one of the centers reported that they faced economic barriers to the cost of the procedure to comply with the physician's referral. Even when the cost of the procedure is reduced, particularly if the mammography is done in the radiology center recommended by the health center's personnel, the reimbursement of \$40.00 can signify a burdensome amount on the family budget. One woman commented that she had the referral for two months before having the exam because *"one doesn't have \$40 sometimes, one has to wait to put that amount of money together, at least for me, I'm not working right now."* Another woman also reacted when she heard another interviewee say that she had the first mammography and all later tests without cost or deductible through a program in the San Juan Medical Center (which was referred to as "Cancer Prevention"):

"Hey, and I'm paying \$40! Last month they gave me this referral that I have to have it again and because I don't have \$40 I haven't been able to have it. Do you have the phone number?"

Economic difficulties that impeded or delayed the use of the mammography referral were not mentioned by the interviewees in the other center. Through the government plan, the participants indicated that they paid a deductible of \$.50 to \$3.00, but that some people didn't have to pay anything. There was a woman in the age 40-49 group who said that she asked to have a mammography every six months. Her doctor gave her a referral if she had any pain and the exams were covered by her insurance.

2. Access to services: distance and cost of transportation

The participants from both centers mentioned that on occasions, the indirect costs involved in referral compliance can delay or impede timely compliance. The costs included the distance and the cost of transportation.

⁴ The CESCA card is a private medical insurance plan paid for by the government for medically indigent persons. It is a managed care plan. Although the participants referred to the CESCA Plan, this plan actually does not exist anymore, the plan now in use is known as Blue Net.

Travel to a radiology center to comply with a mammography referral did not signify a barrier to the interviewees in the center located in the metropolitan area, but the participants acknowledged that distance and transportation would be obstacles for other women that go to that center. According to the participants, there are women who miss work, who have children or grandchildren to care for and look for someone to take care of them while they go to appointments and this can be an impediment for complying with referrals on time. There would also be difficulties for sick persons who have trouble traveling in buses and walking distances in the centers. As a matter of fact, locating a mammography clinic in the primary health center was one of the recommendations given to increase access to mammography screening for women in this population.

The interviewees in the other center (non-metropolitan area) indicated that for some women in their area, "the distance factor" would impede them from complying with the referral if the person did not have the economic resources to pay for the transportation or have someone to provide transportation.

"There's a population who comes here who cannot necessarily do it, it could be that I'd have some...how do I explain this...it costs me 55 cents to come here from my house (...) It's still a question of money (...) This is a population of relatively elderly people who can hardly...and many of them do not receive social security...many of them have children...but maybe there are other people who don't even have anyone to bring them, there aren't senior citizen centers, buses that go to get people at their houses. If someone doesn't have a neighbor or a bus that goes to the sector where they live, (...) that can take them to town and then take them out of this area [referring to the mammography radiology center], it would have to be someone who has a family member, or a neighbor who'll do them a favor or if she can economically manage...and that's not the situation with the majority of the women."

The cost of the deductible was not necessarily a burden in itself but together with other costs this could impede timely referral compliance, particularly if a woman did not feel any other symptoms. Some of the interviewees, especially the younger group (age 40-49) commented about how a woman couldn't have a mammography even having a referral when she also had other referrals [vaginal sonogram, for example] that "compete" for the extra resources from the same limited budget.

3. Other systemic barriers

Other barriers relating to the treatment from service providers can be considered as systemic since the service provider is an element of the health care providing system.

a. Treatment during mammography

One situation that could become a barrier for impeding adequate compliance with a referral is the level of satisfaction with the treatment received during a mammogram.

This is especially critical when seeking to minimize barriers to the regular and sustained use of mammography as a screening strategy.

The women indicated their dissatisfaction with how some of the technicians excessively compressed the breasts during the exam. Some reported that they had received bruises on their breasts and that they had spent several days with pain after the screening exam.

"The only bad thing about these tests is that they squeeze too much. "You know, I had pain in my breast for about a week. I could hardly put on my bra and I had to leave them [the breasts] loose."

b. Communication on the part of health professionals

The participants expressed a lack of communication and orientation from health professionals about mammography as a screening strategy. This deficiency acts as a systemic barrier given that it impedes establishing sustained habits for the use of mammography as a screening strategy. Very few of the women interviewed have had a mammogram for the purpose of secondary prevention. Even for women age 50-64 with recommendations for annual screening and who are asymptomatic, the focus groups revealed that these women believe that they have been referred for mammography because of some symptom or because the doctor detected something. Nevertheless, at one of the centers, one woman from the 50-64 age group indicated that the doctor explained what the exam was for when he sent her to have a mammogram for the first time:

"Yes, of course. Well, it's to detect something. Lately they are doing them routinely."

c. Physician-Patient Relationship

The physician-patient relationship could be a barrier; if there is not adequate communication, it could inhibit correct practices of mammography as a method for early detection. There were no differences by age groups relating to the doctor-patient relationship. Nevertheless, the participants from one of the health centers complained much more about the doctors than the women from the other center.

The majority of the women complained that the clinicians weren't communicative. Some of them indicated that "they didn't talk":

"They don't even talk."

Moderator: "And you would like them to talk?"

"Of course."

"Yes, it would be good, so that you can leave with peace of mind, it wouldn't be asking too much."

Moderator: "What else should we tell the doctors?"

"That they should be more concerned because there are some who only give you prescriptions and don't even look at your face."

"Explain more to the patient about new diseases."

"Talk more."

Some women expressed that the doctors had not talked to them about the importance of mammography:

Moderator: "No doctor has told you before about mammography?"

"No, if he told me, I don't remember."

Moderator: Has the doctor ever suggested that you have a mammogram?

"No."

Some participants also expressed that the physicians did not inform them about the results of the mammogram. Another aspect about the lack of communication with patients, particularly relating to mammography, is that the doctors did not ask when the woman had her last mammogram. Also, they forget to recommend mammography to women between the ages of 50 and 64.

"Another thing about the doctor: that the doctor asks when was your last mammography, because they don't ask you."

It was also pointed out that when a doctor said that he/she was not going to make a referral for a mammogram, there was no explanation. This was mentioned by a woman in the 40-49 age group.

"I asked the doctor, but he told me that it wasn't necessary."

Moderator: "Why wasn't it necessary? Did the doctor say?"

"He didn't say anything."

One of the participants expressed that it was the nurse, not the doctor who explained the results of the mammography:

"You know that nurse explained it to me; even showed me, said look at this."

One woman in the 50-64 age group pointed out that the doctors do not offer information about age and mammograms:

Moderator: "Speaking of this, in terms of the doctors, do you feel that they answer all of your questions about mammography, that they have respond to your concerns or is there still something more that you think should be explained?"

"I want to ask them at what age a woman should start having mammography."

Moderator: "They haven't answered this before then."

"No."

Some participants expressed that the doctors do not do clinical breast exams. The following were comments from the participants in one of the centers:

Moderator: "But this is for the arm and about mammography, they didn't say anything? They didn't do a breast exam?"

"Nothing."

Moderator: "And the breast exam. Is it regularly done here, the exam by the doctor?"

"No, the doctor doesn't do it."

Another complaint relating to doctors, in addition to the lack of communication, was about the unfriendly treatment on the part of service providers:

"Yes, there are doctors who are really harsh."

Some of the women complained that the doctor-patient relationship was impersonal and expressed their desire for a relationship characterized by "personalism".

"That they should be more concerned because there are some who only give you prescriptions and don't even look at your face."

The study previously mentioned about beliefs and knowledge about breast cancer for women age 65 and older in Puerto Rico found something similar for elderly women (Sánchez-Ayénde et al. 1996)..

"Some of the participants talked about maintaining a personal relationship with their physician; a relationship based on affection and trust which were deemed as requisites for dealing with issues such as breast cancer and exams. Puerto Rican cultural traditions emphasizes personal relations. These relationships are based on "personalismo"; the notion that what is important is the singularity of each human being, his/her interior quality. Puerto Ricans, particularly those who now integrated the cohort 65 and older, prefer to deal with other in terms of a network of personal relationships (Sánchez-Ayénde, 1984). The aged tend to view their service providers as not only someone who provides services but one with whom they fell comfortable (Sánchez-Ayénde, 1984).

Some of the participants indicated that not only was the doctor was incommunicative with them, but the mammography technician as well:

Moderator: "But they didn't explain it?"

"She didn't explain it to me." [the technician]

In spite of the complaints, some participants demonstrated assertiveness in the physician-patient relationship. One woman expressed the following:

"OK, you have to tell the person, the doctor, that you are interested in having a mammography because you haven't had one in some time so that the doctor gives you the referral, because you have to do that, they're not going to give one on their own. You have to tell the doctor: look, I want you to give me a referral because I want to do such and such test."

Another woman said that she does not always pay attention to her physician:

"The doctor tells me. He sends me to have the exam and I haven't done anything. He tells me, you have to have it and I tell him, I don't have anything wrong, doctor."

Another woman commented that she had changed doctors because he refused to give her a referral for mammography that she understood she needed to have.

Two participants indicated that their doctor explained the mammograms. One said:

"When it's voluntary they just put it in the record, but when he [the doctor] orders it for some pain, he tells me that I came out well and explains it to me."

Another participant indicated that her doctor pays attention to the results:

Moderator: "And does the doctor pay attention that you return with the results?"
"Yes."

"After they send you to the gynecologist, if they see something, they want the gynecologist to see you."

d. Sources of Information

A systemic barrier is that the main source of information about mammography, as reported by the participants, were not the health centers and their personnel, but the television, radio, neighbors and friends.

The majority of the participants indicated that most information about breast cancer and the needs for having mammograms was received through the mass media: television and radio. The women mentioned specific programs that they had seen or heard.

For health specialists, these channels of information are complementary means of diffusion but they cannot substitute the reliability and effectiveness of communication that

should take place in a doctor-patient encounter. Service providers can face problems with the over-utilization by some health users due to the diffusion of messages that promote annual or bi-annual mammography for all women age 35 to 40 and older, asymptomatic or not, if the health center adheres to annual screening policies only for women age 50 and older. The lack of communication and orientation for users and providers about these discrepancies could create a lack of confidence of users toward the health professionals and could become a barrier. The comments of one woman in the age 40 to 49 group is particular revealing about this topic:

"There's a lot of information in the press, an incredible bombardment of information and everything, but the doctor, ah! the doctor says, that the mammography isn't necessary once a year. I have to ask my doctor to send me."

From these observations, one cannot determine exactly which are common behaviors of women in this age group. Nevertheless, if there is a strategy on the part of health providers to overcome this type of disinformation and conflicting messages, the possibilities can be minimized. Several participants also indicated that the hospitals and health centers disseminated written information and that the health centers sometimes offered conferences about breast cancer. In spite of expressing that the physicians were not communicative, there were women who did indicate that they received information from their doctors.

The participants also indicated the need to disseminate information about breast cancer and early detection exams in churches and community centers. They mentioned that it was necessary to provide information about the existing resources in a community for having a mammogram.

Physicians' Focus Group

Objectives

The objectives for the physicians' focus group were the following:

1. To obtain qualitative data about knowledge and compliance with breast cancer screening guidelines.
2. To obtain qualitative data about the appropriateness of an instrument of semi-structured and open-ended questions with the simulation of case studies to obtain the factors that explain screening mammogram referral patterns and knowledge about screening guidelines (NIH Consensus, 1997) among physicians in different clinical settings in the following categories:
 - a. Women age 40-49 (discuss and explain risk profiles; referral if appropriate)

- b. Women age 50-64 (referral)
- c. Attitudes, patient-physician relationship, clinical setting (region)

The main goal of the physicians' focus group was to obtain qualitative information to design an appropriate instrument to be used to answer two research questions considered in this project:

1. Are physicians following the 1997 NIH guidelines for screening mammograms for women age 40-49 and 50-64?
2. Will physicians correctly follow the 1997 NIH guidelines for screening mammogram referrals for more than 89% of their patients?

Information from a survey of 50 physicians will be used to conduct subgroup analyses by patient age-group (age 40-49 and age 50-64), physicians' characteristics (gender, age, specialty, etc.) and clinical setting/region to evaluate the research questions.

Focus Group Session

A focus group with eight physicians was conducted. Dr. Cruz M. Nazario, cancer epidemiologist, was the moderator. Other members of the research team were also present in the activity. The activity consisted of two parts, the completion of the preliminary instrument independently by each physician and the group discussion of the previously completed instrument. The activity lasted three hours. All of the physicians invited to participate attended the focus group session.

The session started with the introduction of each participant (Table 1) and was followed by a short presentation by the principal Investigator. The objectives of the focus group were explained, as well as the requirements that the grant imposed on the activity. An Informed Consent was obtained from each of the participating physicians. They also agreed to the tape recording of the discussion.

Table 1. General Information for Physicians

	Total (%)
Specialty	
Family Medicine	4 (50.0)
Internal Medicine	3 (37.5)
Gynecology	1 (12.5)
Years of Practice	
mean 14.8 years (minimum 4, maximum 20)	8
Gender	
Male	5 (62.5)
Female	3 (37.5)
Age	
mean 44.9 years (minimum 40, maximum 51)	

The session continued with the completion the instrument, a semi-structured and open-ended questionnaire with 16 case studies. This part lasted approximately 15 to 20 minutes and even though the questionnaires were answered independently, comments were made regarding a particular case study. This did not affect the process because the distractions were minimal. We were able to observe diverse patterns with which the participants completed the instrument. Some participants answered in a systematic manner, answering the instrument from case study Number 1 to case study Number 16. Others were observed going back and forth to previous case studies. During this part of the activity, some physicians asked about the meaning of particular questions (i.e., Would you recommend other tests?) that apparently caused some confusion. This issue will be discussed further in this report. After the participants finished the questionnaire, a group discussion on the difficulty of some of the situations presented in the case studies and on the similarities with real life situations ensued. This discussion lasted approximately two and a half hours. The physicians also recommended that a case study be added for a patient with Alzheimer disease or AIDS in order to elicit patterns of discrimination against such patients.

Group Discussion

During the discussion session, participants recommended minor changes to the instrument and suggested some modifications. For example, in the instructions on how to answer the questionnaire, it was suggested that we should not mention the specific socioeconomic level (low socioeconomic, middle-aged) of the target group, since

differences exist in the way the guidelines are being applied due to capitation limits after the Health Reform was established in Puerto Rico. It was also suggested that we explain in the instructions that the physician should evaluate the case studies as if she or he was the primary physician in charge of the health care of that patient.

The difficulty of applying statistics came up during the session. For example, the concept of false positive rates for screening mammograms was confused with that of diagnostic tests. Also, the breast cancer survival rates among different age groups were used as a reason for a referral to screening mammogram instead of the risk factors. It was also observed that the participants' personal style and personality influenced the way they argued for or against recommending a screening mammogram for a female patient.

In general terms, the focus group helped us identify areas where the instrument needed improvement while minimizing bias (desirability). The group did not consider the instrument too long, too time consuming, or that any case studies had to be eliminated. Nevertheless, their clinical settings could be different from our target group of physicians. They discussed the case studies and agreed that some were more difficult to answer than others. One physician mentioned that while he answered that he would recommend a screening mammogram in some case studies in the instrument ($>$ age 50), if a real patient argues against it, he would probably not try to convince her.

It was clear from the focus group that referral patterns vary according to the type medical practice and clinical setting, and with the particular characteristics of the patients. The issues of cost, cost-effectiveness, capitation and type of health insurance were a major concern for most of the focus group participants. Such issues are probably modifying the way physicians are following the referral guidelines for breast cancer screening mammograms. The group commented on the difficulties that physicians are facing in practicing "good medicine" with such restrictions. One participant said that if the patient could not be "reasoned with", he would not "push" the referral. Many comments revolved around the issue of physicians being afraid of being accused by patients of improper conduct if they attempted to do a clinical breast examination. The availability of a "chaperon" or a nurse to help and to be present during the physical exam was a real concern among participants who believed that this issue could impinge on this practice.

The original instrument contained a question regarding other tests. The participants expressed that this question should be eliminated as it could have different interpretations. Some considered this question to mean interventions that could include "talking with the patient to convince her about the benefits of screening." Others interpreted it as routine blood tests such as for cholesterol.

The focus group activity allowed us to test the instrument that we will use to elicit screening mammogram referral patterns while reducing observer and interviewer bias. The case studies provided a variety of situations where the physicians had to decide whether they would give a diagnostic or screening mammogram referral and a sonomammogram referral. According to the participants and the focus group evaluation of the research team,

the instrument is appropriate to test if physicians are following the NIH Consensus Guidelines for breast cancer screening in women age 40-49 and over age 50 in Puerto Rico.

Evaluation of the participants' answers

In general, the instrument was able to capture a wide variety of responses and referral patterns for screening and diagnostic mammograms. Participants were interested by this method (simulated case studies) and motivated to comply with our request. We explained that we wanted them to consider the cases described as if the women were patients from their clinical practices and that the recommendation for a referral for each particular case study should represent the guidelines for screening and diagnostic mammograms that they are following given the characteristics of each case.

It was also evident that risk factors for breast cancer are not easily recognized and that the instrument was able to detect such discrepancies. Some case studies were not adequate for discriminating among physicians since all were answered in the same manner, that the patient needed a referral for a screening mammogram. The patients described in these case studies were over age 50, which is the strongest and most accepted risk factor for breast cancer. Over 50 years of age is the most accepted and recognized risk factor within the guidelines for breast cancer screening. Nevertheless, it was decided that the instrument should include an option for a diagnostic mammogram as well as an option for "follow-up".

Most of the participating physicians in the focus group did not recommend a screening mammogram in case studies when the females were less than age 50 and had no symptoms, with the exception of physicians who considered that breast cancer screening should start at age 40. If the patient was younger than 50 and had symptoms, all physicians recommended a screening mammogram regardless of the age group. This referral pattern could be explained either because they are not aware of the difference between a screening and a diagnostic mammogram or because there was not an explicit category for diagnostic mammograms. Even though the instrument did not have an alternative for diagnostic mammogram, there was an option to explain their referral. It was decided that an alternative for diagnostic mammogram to detect the referral pattern for both alternatives in the absence or presence of symptoms should be added to the instrument. This situation was also observed during the discussion session, in which participants discussed the screening mammogram option when a diagnostic mammogram was the actual alternative they chose for the case study.

Risk factors, such as previous diagnosis of atypical hyperplasia, nulliparity and personal history of breast cancer, were correctly identified with the exception of family history (lineage). It appears that risk factors were sometimes used as the reason for referral rather than age with women over age 50. We decided to modify some of the case studies so that we could determine if the reason for referral was the age factor (>age 50)

or the risk factor (i.e., personal history of breast cancer). We also agreed to include at least one case study with each of the following combination of characteristics:

- female >age 50 without symptoms or risk factors
- female > age 50 with symptoms
- female age 40-49 without symptoms or risk factors
- female age 40-49 with symptoms
- female age 40-49 without symptoms+family history (correct)
- female age 40-49 without symptoms+family history (incorrect)
- female age 40-49 without symptoms+radiation to the mediastinum
- female age 40-49 without symptoms+atypical hyperplasia
- female age 40-49 without symptoms+nulliparous
- female age 40-49 without symptoms+ fibrocystic disease (not a risk factor)
- female <age 40 without symptoms+ risk factors (unproven but probable)
- female < age 40 with symptoms

Another observation from the questionnaire was the incorrect use of statistics to qualify the risk status of the patient. One participant mentioned that the incidence of breast cancer was one in eight (for the case study of a woman age 55), an incorrect data for Puerto Rican females in that age group.

The revised instrument should provide us with the opportunity to verify the patterns that physicians are using as guidelines for asymptomatic patients in the two age categories: 40-49 and ≥ 50 years of age, as well as identify the reasons for referral. Also we are able to evaluate differences among diagnostic and screening patterns for referrals.

Results from individual case studies

- Case studies #3, 7, 14. Female patients >age 50 with no symptoms or other strong risk factors except age. All focus group participants (total of 8) correctly recommended a screening mammogram.
- Case study #4. Female patient >age 50 with symptoms.
 5/8 participants correctly answered that they would recommend a diagnostic mammogram, but two (2) of those five (5) used the wrong arguments for the referral.
 2/8 incorrectly recommended a screening mammogram and did not explain the reasons for the referral.
 1/8 did not answer the question.
 Even though there was not an explicit option for diagnostic mammogram, we had evidence that the physicians could correctly explain or qualify their referral as diagnostic instead of screening. Nevertheless, the instrument should be modified to include an option for diagnostic mammogram as well as an option for "follow-up".
- Case study #1. Female <age 50 without symptoms and without strong risk factors.

3/8 participants correctly answered that they would not recommend a screening mammogram.

3/8 participants incorrectly answered that they would recommend a screening mammogram since screening should start at age 40.

2/8 participants incorrectly answered that they would recommend a screening mammogram without any explanation for the referral.

- Case study #9. Female <age 50 with symptoms.
5/8 participants correctly answered that they would recommend a diagnostic mammogram.
- Case study #10. Female <age 50 with symptoms.
4/8 participants correctly answered that they would recommend a sonomammogram.
- Case study #16. Female <age 50 without symptoms and with strong risk factor (BRCA1)
7/8 participants correctly answered that they would recommend a screening mammogram. Nevertheless, some explained that the reason for the referral was because "screening should start at age 40".
- Case study #2. Female <age 50 without symptoms and without strong risk factors.
8/8 All participants incorrectly answered that they would recommend a screening mammogram. This was because some consider that "screening should start at age 40", others because she was close to 50 years of age, and some of the participants confused the family history lineage.
- Case study #11. Female <age 40 without symptoms and with strong risk factor (Radiation treatment to the mediastinum for Hodgkin's Disease).
4/8 participants incorrectly answered that they would recommend a screening mammogram.
3/8 would not recommend the screening mammogram, but then one of those recommended a screening mammogram at age 30.
1/8 did not answer the question.
- Case study #13. Female <age 50 without symptoms and with strong risk factor (previous biopsy with atypical hyperplasia).
7/8 participants correctly answered that they would recommend a screening mammogram.
1/8 did not answer the question.
- Case study #6. Female <age 50 without symptoms and with strong risk factor (nulliparous).
6/8 participants correctly answered that they would recommend a screening mammogram. This case-study used the well recognized example of the nun, thus the risk factor was easily identifiable.
1/8 incorrect answer.
- Case study #5 - Female <age 50 without symptoms and without strong risk factor (previous carcinoma in situ of the cervix uteri is not a strong risk factor for breast cancer).

2/8 participants correctly answered that they would not recommend a screening mammogram.

5/8 participants incorrectly answered that they would recommend a screening mammogram, because the patient's history of cervical carcinoma.

1/8 One participant explained that the reason for the referral was because, "screening should start at age 40".

- Case study #8. Female <age 50 without symptoms and without risk factors (family history of fibrocystic disease in not a risk factor for breast cancer, even personal history of fibrocystic disease in not a risk factor for breast cancer).
2/8 participants correctly answered that they would not recommend a screening mammogram.
3/8 participants incorrectly answered that they would recommend a screening mammogram without any explanation for the referral.
2/8 participants incorrectly answered that they would recommend a screening mammogram and explained that the reason for referral was the family history of fibrocystic disease.
1/8 One participant explained that the reason for the referral was because "screening should start at age 40".
- Case study #12. Female <age 40 without symptoms and with a potential exposure to hormone treatment as a child (Telarche treatment with hormones).
7/8 participants correctly answered that they would not recommend a screening mammogram. Even though telarche has not been evaluated as a risk factor for breast cancer, it could be an indicator for exposure to hormones at a very young age (< age 8).
1/8 participants incorrectly answered that they would recommend a screening mammogram.
- Case study #15. Female <age 50 without symptoms and without risk factors.
3/8 participants correctly answered that they would not recommend a screening mammogram.
3/8 participants incorrectly answered that they would recommend a screening mammogram.
2/8 participants did not answer.

Table 2. Participant's Answers to Case Studies

Case studies	Individual Participants (X=incorrect, Y=correct answer but wrong reason for referral, ?= no answer)							
	A	B	C	D	E	F	G	H
Age 42, G3P3A0, asymptomatic, without risk factors		X	X ¹	X ¹		X		X ¹
Age 48, G4P4A0, asymptomatic, without risk factors + incorrect family history (paternal aunt w/ breast cancer)	X	X	X ¹	X ¹	X ²	X	X ²	X ¹
Age 55, G3P2A1, asymptomatic						8		
Age 62, G2P2A0, symptoms		5		X	X	X/Y	X/Y	?
Age 45, G1P1A0, asymptomatic, without risk factors		X	X	X ³	X ³	X ³		X ¹
Age 48, G0P0A0, asymptomatic, risk factor	X						X	
Age 71, asymptomatic					? ⁷			
Age 47, G6P5A1, asymptomatic, without risk factors		X	X	X ¹	X ⁴	X		X ⁴
Age 33, G2P2A0, symptoms → diagnostic mammogram	X/Y		5		5	X	5	X
Age 18, G0P0A0,, → sonomammogram	X/Y		5	X/Y		X	?	X
Age 25, G0P0A0, history radiation to mediastinum	X	X		6	X		X	?
Age 28, G0P0A0, history of telarche								X
Age 41, G6P4A2, Bx atypical hyperplasia	?							
Age 58, G8P7A1, asymptomatic				¹				²
Age 45, G4P4A0, asymptomatic, without risk factors		X	?	X	X			?
Age 47, G4P3A1, asymptomatic, risk factor (Fm history BRCA1)	X			¹	X/Y	X/Y		

Notes:

1. Participant states screening should start at 40 years of age.
2. Incorrect interpretation of family history/lineage as risk factor.
3. Incorrect interpretation of risk factor carcinoma. In situ of cervix uteri is not a risk factor, invasive carcinoma of cervix is a minor risk factor.
4. Incorrect interpretation of family history of fibrocystic disease as risk factor; even personal history of fibrocystic disease is not a risk factor.
5. Physicians who explained that the procedure had to be diagnostic.
6. Participant states screening should start at 30 years of age for this patient.
7. Participant states that risk decreases with age.
8. Participant states risk for the patient is 1 in 8.

Table 3. Participants' Answers to Open-Ended Questions

Participant Code	A	B	C	D	E	F	G	H
Type of practice	1	2	2	2	2	3	4	4
1. a. Percent of female patients <age 50 (past 12 months)	20	25	20	20	10	60	50	x
b. Percent of patients that comply with mammogram referral	2	40	90	30	100	95	75	x
c. Reasons for non-compliance								
cost/income/not covered by insurance	x	x	x				x	
not the primary physician	x							
access		x						x
fear of test results		x	x	x				
procrastination			x			x		
no perceived need to have the test/no symptoms				x				
long wait for the appointment						x		
problems with transportation							x	
afraid of a painful test				x				
fear of radiation							x	
2. Guidelines for screening women <age 50								
once a year after age 40/every year		x	x					x
high risk factors (family history, personal history)	x			x	x	x	x	
physical findings/symptoms				x		x		
every 2-3 years								
CBE every year		x						
BSE monthly		x						
3. Guidelines for screening women ≥ age 50								
every 1-2 years	x	x	x	x	x	x		x
age	x						x	

RESEARCH INSTRUMENTS

After the interpretation of results, the physician's questionnaire was reduced to 12 case studies. The final version appears in Appendix 2. It consists of three parts: brief demographic data, case studies and five open-ended questions.

The instrument to compile information from medical records was prepared using a model from the compilation of statistics from the Breast Cancer Screening Program in the Municipality of San Juan⁵. This instrument was modified from the original version to meet the objectives of this research project. Two visits were carried out, one each in the metropolitan and non-metropolitan area health centers, to determine if the design of the instrument was adequate. During the review of the records, the instrument was modified to facilitate the compiling of information necessary to determine participant's eligibility and the data to establish contact with the participants. (See Appendix 3). The instrument focused on the following areas: demographic data, eligibility criteria and the person's contact information.

The analysis of the women's focus groups facilitated the design of the questionnaire for middle-aged women with low socioeconomic conditions in the selected geographic regions. The focus groups served to incorporate pertinent issues and appropriate vocabulary. Also incorporated were issues that were found in literature about mammography compliance and the work carried out in Puerto Rico by Vélez-Almodóvar (1997) and Aulet-Robles (1999). The questionnaire was tested on ten women with backgrounds similar to the future participants to verify appropriateness in social and cultural terms, particularly vocabulary and issues related to women with low socioeconomic conditions in Puerto Rico. This test also served to verify the appropriateness of the order of the questions. Pertinent adjustments were made to the original questionnaire. The final version (Appendix 4) consists of the following sections:

- A. Sociodemographic information
- B. Family and individual history
- C. Early detection practices
- D. Perception of patient-doctor relationship
- E. Attitudes toward health
- F. Knowledge about breast cancer
- G. Sources of information
- H. Access to services
- I. Health status
- J. Knowledge about services
- K. Socioeconomic information

⁵ The document was provided by the Director of the metropolitan area center utilized for this study.

TRAINING OF PERSONNEL

Two training sessions were carried out. One session was directed to the individuals who would compile information from the medical records and the other for the individuals who would administer the questionnaires to the doctors. Manuals were prepared for both training sessions. The procedures for quality control and coding, as well as administrative procedures and specific matters pertaining to each instrument were explained in the training.

SAMPLE SELECTION OF PHYSICIANS

The selection of 50 physicians for the administration of the questionnaire was by convenience. Part of the physicians sample was selected from different centers that offer services in the metropolitan area selected for this study. The Executive Directors and Medical Director were approached in each center. They provided a list of the physicians in the centers and selected family physicians, generalists, internists and gynecologists from this list who usually cared for middle-aged women. A similar procedure was followed for the non-metropolitan area.

FINAL REMARKS / CONCLUSIONS

The first year of the project focused on the selection of sites to carry out the research, development of collaborative ties with the health centers administrators, and the design of the research instruments. All projected tasks were conducted.

Focus group results indicate that the low-income middle aged women view cancer as a cell disorder and that breast pain or discomfort is a factor associated to the disease. The women have knowledge of breast self exam, clinical breast exam and mammogram as early detection tests as well as of the usefulness of mammograms. No clear knowledge of NIH 1997 screening mammogram guidelines was found among the participants. Apprehensions about the discomfort caused by the mammography procedure and fear of a cancer diagnostic were the most prevalent personal barriers for mammogram compliance were: economic factors, transportation and patient-physician relationship.

The second year of the project will revolve around data gathering: physicians interviews, analysis of medical records, and survey of low-income middle-aged women.

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APPENDIX 1

From: Miles Cheryl R <Cheryl.Miles@DET.AMEDD.ARMY.MIL>
To: 'MELBA SANCHEZ-AYENDEZ & ALBERTO GARCIA-MOLL' <m_sanchez@worldnet.att.net>
Date: Thursday, July 01, 1999 1:36 PM
Subject: RE: DAMD17-99-9359

Courtesy Copy

Enclosed is the recommended budget for this award. The technical staff concurs with the Peer Review Panels recommendation to limit this project to 3 years. Based on your previous response, it is understood that Tasks 5 & 6 will be deleted.

The COLA was adjusted to reflect 3% as recommended by the Contacting Officer.

Please let me know if you are willing and able to accomplish Tasks 1 - 4 in 3 years and within the recommended budget. If the budget is acceptable and the statements underneath it are accurate, please return a signed copy of the document as soon as possible.

The projected start date for this award is 1 August 1999.

-----Original Message-----

From: MELBA SANCHEZ-AYENDEZ & ALBERTO GARCIA-MOLL
[mailto:m_sanchez@worldnet.att.net]
Sent: Thursday, June 24, 1999 8:52 PM
To: usarmc: cheryl miles
Cc: Myriam Rivera-Cano; ana luisa davila
Subject: DAMD17-99-9359: proposed budget revision

TO: Ms Cheryl Miles
RE: DAMD17-99-9359:
"Mammography Compliance among Low-Income Middle Aged Women in Puerto Rico"

Our research team met yesterday and today to work on a new statement of work (SOW) and revised budget for a 4 year period that includes Tasks 5 & 6 of original proposal as well as on budget justification.

I include the proposed budget for 4 years instead of the original 5 or the 3 year period that did not include tasks 5 & 6 because it is not feasible within that time limit. We had to comprise activities of two years in one year as is the case for year 2 (tasks 2 & 3 in one year) and year 4 (prior years 4 & 5; tasks 5 & 6) and certain costs had to be incorporated from the year that was left out if we wanted to carry out certain activities needed for either data analysis or intervention strategies. Please let us know what is agreeable to USAMRMC in order to submit new SOW according to budget: 3 years without tasks 5 & 6 or 4 years with tasks 5 & 6. Our project was supposed to begin on July 1, 1999 and now we must consider August 1, 1999 or a later date. We prefer August.

4/26/00

APPENDIX 2

Project Title: *Mammogram Compliance Among Middle-Aged Women in Puerto Rico*

Grant Number: U.S Army Medical Research and Materiel Command
DAMD17-99-1-9359

Principal Investigator: Melba Sánchez Ayéndez, Ph.D.
Graduate School of Public Health
University of Puerto Rico

Control Number:

- -

Mark all of the appropriate boxes to indicate your speciality and/or type of clinical practice:

Family physician	<input type="checkbox"/>	Oncology	<input type="checkbox"/>
Gerontology	<input type="checkbox"/>	General Medicine	<input type="checkbox"/>
Obstetrics/Gynecology	<input type="checkbox"/>	Other	<input type="checkbox"/>
Internal Medicine	<input type="checkbox"/>		

Age: ____

Gender:

Female ☐
Male ☐

General Instructions:

- I. Evaluate each of the following cases as if you were the primary physician of the patient in charge of her ongoing care. Please answer the questions to the right in each case. (CBE = Clinical Breast Exam; BSE= Breast self-exam)

Case 1:

41 year old architect, G3P3A0, first pregnancy at age 26. Her mother died of pulmonary embolism at age 59, and her father died of laryngeal cancer at age 72. She is very afraid of radiation and asks if she could wait until age 50 to get her first mammogram.

1. Would you recommend that this patient have:

- | | |
|----------------------------|--|
| a. A screening mammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| b. A diagnostic mammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| c. A sonomammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| d. Follow-up/CBE/BSE | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- | | |
|-------------------|--|
| a. Age | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |
| b. Risk Factor | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |
| c. Symptoms/Signs | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |

Case 2:

48 year old Columbian immigrant, G4P4A0, housewife, first pregnancy at age 16. Arrived in PR in 1994 but does not have medical insurance. She claims that she has never been sick before, but is very concerned because a paternal aunt was diagnosed with breast cancer last month.

1. Would you recommend that this patient have:

- | | |
|----------------------------|--|
| a. A screening mammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| b. A diagnostic mammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| c. A sonomammogram? | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |
| d. Follow-up/CBE/BSE | No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> |

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- | | |
|-------------------|--|
| a. Age | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |
| b. Risk Factor | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |
| c. Symptoms/Signs | No <input type="checkbox"/> Yes <input type="checkbox"/> Specify _____ |

Case 3:

62 year old housewife, G2P2A0, with a negative mammogram 2 months ago. Complains of pain in left breast since her 1½ year old grandson "kicked" her in this breast five weeks ago. The breast is red, indurated and looks larger than the right breast.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up/CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 4:

40 year old secretary, G1P1A0, (gave birth at age 33), visits her gynecologist regularly. During each check-up she receives a clinical breast exam. The last exam was negative. Two weeks ago she found a dark spot on her bra. Squeezing the nipple produces a drop of reddish liquid.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 5:

45 year old executive who keeps herself very slim with a vegetarian diet, sports, civic and cultural activities.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 6:

64 year old widow, G1P1A0, with DM, dependent on insulin since age 41; obese. Patient has recently been diagnosed with Alzheimer and her daughter is going to put her in a home for the elderly. Her only insurance is PR Health Reform.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 7:

43 year old housewife, G6P5A1, whose first pregnancy was at age 17. Patient says that she has fibrocystic disease but has not had a breast biopsy.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 8:

18 year old student who has been sexually active since age 15, has an egg-like mass in the lower inner quadrant of the left breast.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 9:

40 year old teacher, G2P2A0, with a history of Hodgkin's disease in the mediastinum, treated with radiation therapy at age 13. Patient has annual follow-up visits.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 10:

28 year old nurse, G0P0A0, with a history of thelarche during childhood. Patient does not complain of any breast discomfort, but is considering undergoing surgery to increase breast size.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
 - b. Risk Factor No ☐ Yes ☐ Specify _____
 - c. Symptoms/Signs No ☐ Yes ☐ Specify _____
-

Case 11:

41 year old journalist, G6P4A2 who had a breast biopsy five years ago. The pathological diagnosis was atypical hyperplasia.

1. Would you recommend that this patient have:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
- b. Risk Factor No ☐ Yes ☐ Specify _____
- c. Symptoms/Signs No ☐ Yes ☐ Specify _____

Case 12

47 year old minister, G4P3A1. Her 28 year old daughter was diagnosed with breast cancer two weeks ago. Last week the daughter was informed that the BRCA1 test was positive.

1. Would you recommend that this patient do:

- a. A screening mammogram? No ☐ Yes ☐ Don't know ☐
- b. A diagnostic mammogram? No ☐ Yes ☐ Don't know ☐
- c. A sonomammogram? No ☐ Yes ☐ Don't know ☐
- d. Follow-up CBE/BSE No ☐ Yes ☐ Don't know ☐

2. If you would recommend any or various of the above mentioned exams, mark the reason for the referral:

- a. Age No ☐ Yes ☐ Specify _____
- b. Risk Factor No ☐ Yes ☐ Specify _____
- c. Symptoms/Signs No ☐ Yes ☐ Specify _____

II. Please answer the following questions:

1. During the past 12 months:

- a. What percentage of your female patients were **less than 50** years of age? _____%
- b. What percentage of your patients who received a referral for a mammogram complied with the referral? _____%
- c. Of those patients who did not comply with the referral, what were the reasons they gave for not getting the exam?
 - i. _____
 - ii. _____
 - iii. _____

2. What are your guidelines for screening mammograms for women **below** age 50? (40-49 years)?

- a. _____
- b. _____
- c. _____

3. What are your guidelines for screening mammograms for women **over** age 50?

- a. _____
- b. _____
- c. _____

4. What are your guidelines for screening mammograms for women **over** age 65?

- a. _____
- b. _____
- c. _____

5. The information that your patients receive about breast cancer primarily comes from: *(Please mark only one of the choices)*:

- ☐ Written educational materials
- ☐ Educational videos in the office
- ☐ You inform each patient according to her specific characteristics
- ☐ You refer patients to the nurse for orientation
- ☐ You refer patients to the health educator
- ☐ You answer patients' questions
- ☐ Other: _____



APPENDIX 3

UNIVERSITY OF PUERTO RICO/MEDICAL SCIENCES CAMPUS
BIO/SOCIAL SCIENCES FACULTY AND GRADUATE SCHOOL OF PUBLIC HEALTH
INTERDISCIPLINARY RESEARCH ON WOMEN'S HEALTH

PROJECT TITLE: MAMMOGRAM COMPLIANCE AMONG MIDDLE-AGED WOMEN IN
PUERTO RICO

GRANT NUMBER: U.S. ARMY MEDICAL RESEARCH AND MATERIEL COMMAND
DAMD17-99-1-9359

PRINCIPAL INVESTIGATOR: MELBA SÁNCHEZ AYÉNDEZ, PH.D.

CONTROL NUMBER: (OFFICIAL USE)

- -

FORM TO EVALUATE ELIGIBILITY OF PARTICIPANTS

1. HEALTH CENTER:

- ☐ (1) Community Health Center Dr. José S. Belaval
☐ (2) Río Grande Community Health Center
☐ (3) Other Center _____

2. RECORD NUMBER:

3. (a) BIRTH DATE: ____ / ____ / ____
(Day) (Month) (Year)

(b) Was the patient born between January 1, 1934 and December 31, 1957?

- ☐ Yes ➡ Go to Question #5
☐ No ➡ Not eligible, end of record review.
☐ Date of birth not available ➡ Go to Question #4

4. (a) If the date of birth is not available, verify the woman's age in the record and calculate the age as of January 1, 1998: ____ Years
(Age)

(b) Is the patient older than 39 or younger than 65 as of January 1, 1998?

- ☐ Yes ➡ Eligible, go to Question #5
☐ No ➡ Not eligible, end of record review.
☐ Date of birth not available ➡ Not eligible, end of record review.

5. (a) Has only one referral ☐ has more than one referral ☐ for a mammogram dated after January 1, 1998

☐ Yes ➡ Date #1 ____ / ____ / ____
(Day) (Month) (Year)
Date #2 ____ / ____ / ____
(Day) (Month) (Year)
Date #3 ____ / ____ / ____
(Day) (Month) (Year)
Date #4 ____ / ____ / ____
(Day) (Month) (Year)

Physician: _____

Physician: _____

Physician: _____

Physician: _____

☐ No referral after January 1, 1998.

(b) **REASONS FOR REFERRAL FOR MAMMOGRAM**

Mark all of the reasons found in the record and note the date (day/month/year)

	DATE		DATE
<input type="checkbox"/> History of breast cancer	_____	<input type="checkbox"/> Persistent pain	_____
<input type="checkbox"/> History of atypical hyperplasia	_____	<input type="checkbox"/> Injury to breast	_____
<input type="checkbox"/> History of lobular carcinoma in situ (LCIS)	_____	<input type="checkbox"/> Changes in the skin/hematomas	_____
<input type="checkbox"/> History of breast biopsy	_____	<input type="checkbox"/> Retraction (collapse)	_____
<input type="checkbox"/> Hardening in breasts	_____	<input type="checkbox"/> Ulceration	_____
<input type="checkbox"/> Presence of mass, growth	_____	<input type="checkbox"/> No symptoms in record	_____
<input type="checkbox"/> Adenopathy in armpit	_____	<input type="checkbox"/> Other: _____	_____
<input type="checkbox"/> Suppuration or secretions from nipples	_____		

6. (a) Are there results from mammograms completed after January 1, 1998?

☐ Yes → Date of last mammogram ____/____/____
(Day) (Month) (Year)

☐ No → If there is a referral for a mammogram (see Question #5) go to Question #7. If there is NO referral (see Question #5) and there are no results from the mammogram, the record review is terminated.

(b) Results of the mammogram: _____

7. Is there any evidence (documents, receipts, notes in progress reports) that there was an individual orientation about early detection screening, risk factors or breast cancer?

☐ Yes → Type of evidence: ☐ Receipt ☐ Progress Report ☐ Other: _____
☐ No

8. **CONTACT PERSON INFORMATION:**

(a) Name: _____
Paternal Last Name Maternal Last Name First Name

(b) Home address: _____

(c) Mailing address: _____

(d) Other address (If not the patient's address, specify name and/or family relationship):

(e) Home telephone: _____ - _____

(f) Work telephone: _____ - _____ Extension: _____

(g) Other telephone: _____ - _____

(g.1.) Place or name of person with this telephone number: _____

COMMENT SHEET RECORD REVIEW

DATE OF RECORD REVIEW: ____/____/____
(DAY) (MO.) (YEAR)

Note: When you write additional information about a specific question on this form, include the question number.

[illegible][illegible]This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

APPENDIX 4

UNIVERSITY OF PUERTO RICO / MEDICAL SCIENCES CAMPUS
BIOSOCIAL SCIENCES FACULTY AND GRADUATE SCHOOL OF PUBLIC HEALTH
INTERDISCIPLINARY RESEARCH ON WOMEN'S HEALTH

CONTROL NUMBER --

Mammogram Compliance Among Middle-Aged Women in Puerto Rico

QUESTIONNAIRE



2000-2001

Funded by: U.S. Army Medical Research and Materiel Command
Grant number DAMD17-99-1-9359

I N T R O D U C T I O N

READ TO PARTICIPANT

We are carrying out a research project about the health practices of women age 40 through 64 in Puerto Rico. The specific topic for our project is breast cancer. We have selected female patients from two health centers to participate in the study: one from the San Juan metropolitan area and from the north coast region. You have been selected to participate in our sample and to answer a questionnaire that has been specially developed for our study.

We have written a series of questions. These questions do not have a right or wrong answer. We are interested in knowing your opinion about certain issues relating to breast cancer.

Your opinion is very important to us and will assist us in planning for better women's health services. We truly appreciate your cooperation. Your participation is voluntary and all information that you give us will be strictly confidential. This interview will last about 30 minutes. Before beginning the interview, it is important that you sign a consent form. This form contains detailed information about how we are carrying out the study.

S I G N I N F O R M E D C O N S E N T F O R M

INSTRUCTIONS FOR INTERVIEWER

THE PURPOSE OF THIS FORM IS TO ASSURE THAT EACH PERSON HAS BEEN CORRECTLY INFORMED ABOUT THE STUDY IN WHICH SHE WILL PARTICIPATE. IT IS IMPORTANT FOR EACH PARTICIPANT TO READ THIS FORM. IF THE PARTICIPANT DOES NOT KNOW HOW TO READ, THE INTERVIEWER SHOULD READ THE INFORMED CONSENT FORM OUT LOUD. WHEN THE FORM HAS BEEN READ, THE PARTICIPANT SHOULD SIGN IN THE SPACE PROVIDED. THE INTERVIEWER WILL SIGN IN THE SPACE PROVIDED FOR THE WITNESS.

THE INFORMED CONSENT FORM MUST BE SIGNED BY THE PARTICIPANT BEFORE BEGINNING THE INTERVIEW.

UNIVERSITY OF PUERTO RICO
MEDICAL SCIENCES CAMPUS
GRADUATE SCHOOL OF PUBLIC HEALTH
INTERDISCIPLINARY RESEARCH ON WOMEN'S HEALTH

MAMMOGRAM COMPLIANCE AMONG MIDDLE-AGED WOMEN IN PUERTO RICO

QUESTIONNAIRE

CONTROL NUMBER

--

A. SOCIODEMOGRAPHIC INFORMATION

THE FOLLOWING QUESTIONS REFER TO DEMOGRAPHIC INFORMATION.

1. What is your birthdate?

DATE: → **GO TO QUESTION #3**
(DAY) (MO.) (YEAR)

INTERVIEWER: IF THE INTERVIEWEE DOES NOT KNOW HER
BIRTHDATE GO TO QUESTION #2

2. How old are you?

3. What is the last grade in school that you completed? (What grade did you finish in school?)

(00) I did not attend school

(01-12) Grade completed, H.S. diploma, equivalency exam

INTERVIEWER: CODIFY RESPONSE 01 = FIRST GRADE TO
12 = 12 TH GRADE/DIPLOMA/EQUIVALENCY EXAM

(13) Technical or Vocational Studies

(14) Associate Degree

(15) Bachelor's Degree

(16) Graduate Studies

(17) Other studies

SPECIFY

4. What is your marital status?

(0) Never married

(1) Widow

(2) Married

(3) Living with partner

(4) Separated

(5) Divorced

5. How many children do you have?

| |

INTERVIEWER: IF INTERVIEWEE HAS NEVER HAD ANY CHILDREN,
CODIFY (00) AND GO TO QUESTION #10

6. What is the birthdate of your first child? | | | | → GO TO QUESTION #8
(DAY) (MO.) (YEAR)

INTERVIEWER: IF THE INTERVIEWEE HAS HAD ONLY ONE CHLD
(SEE RESPONSE TO #5) GO TO QUESTION #10. IF SHE HAS HAD
MORE THAN ONE CHILD, GO TO QUESTION #8

IF THE INTERVIEWEE DOES NOT KNOW THE BIRTHDATE, GO TO
THE NEXT QUESTION.

7. What is the age of your first child?

| |

8. What is the birthdate of your last child? | | | | → GO TO QUESTION #10
(DAY) (MO.) (YEAR)

INTERVIEWER: IF THE INTERVIEWEE DOES NOT KNOW THE
BIRTHDATE GO TO THE NEXT QUESTION.

9. What is the age of your last child?

| |

10. Do you currently work outside of your home ?

|

(1) Yes

(0) No GO TO QUESTION #12

11. What is your occupation?

Occupation _____ GO TO QUESTION #14

12. Have you worked outside of your home in the past?

|

(1) Yes

(0) No GO TO QUESTION #14

13. What was your occupation?

Occupation : _____

14. What medical insurance do you have?

INTERVIEWER: IF THE INTERVIEWEE DOES NOT KNOW OR DOES NOT REMEMBER, ASK HER TO SHOW YOU HER INSURANCE CARD. WRITE ONE (1) IN THE SPACE CORRESPONDING TO THE INSURANCE COVERAGE THAT WAS MENTIONED. WRITE ZERO (0) FOR INSURANCE COVERAGE NOT MENTIONED OR THAT INTERVIEWEE INDICATES SHE DOES NOT HAVE.

- (a) Insurance card from the Government of Puerto Rico ☐
- (b) Medicaid ☐
- (c) Blue Net ☐
- (d) CESCA ☐
- (e) Medicare Part A ☐
- (f) Medicare Part B ☐
- (g) I don't remember ☐
- (h) I don't know ☐
- (i) Other ☐

SPECIFY

B. FAMILY AND PERSONAL HISTORY

THE FOLLOWING QUESTIONS REFER TO THE INTERVIEWEE'S HEALTH HISTORY DURING THE PAST TWELVE MONTHS. (FROM _____ (MONTH, 1999) THROUGH _____ (MONTH, 2000)).

15. Have you felt continuous or constant (almost all of the time) **pain or discomfort** in your breasts for more than 2 weeks in the last twelve months? ☐

- (1) Yes
(0) No
(8) I don't remember
(9) I don't know

16. Have you felt a **lump** (nodule, hardening, bump or mass) in your breasts in the past twelve months? ☐

- (1) Yes
(0) No
(8) I don't remember
(9) I don't know

17. Have you had **secretions from your nipples** (liquids that aren't milk) in the last twelve months? Remember, this is from month, 1999 through month, 2000. |_|

- (1) Yes
- (0) No **GO TO QUESTION #19**
- (8) I don't remember **GO TO QUESTION #19**
- (9) I don't know **GO TO QUESTION #19**

18. What color were these secretions? _____
SPECIFY

19. Have you ever had a **biopsy** of your breast (test with a needle/they cut a little piece of your breast)? |_|

- (1) Yes
- (0) No **GO TO QUESTION #23**
- (8) I don't remember **GO TO QUESTION #23**
- (9) I don't know **GO TO QUESTION #23**

20. When was your last **biopsy**? **DATE OF LAST BIOPSY:** |_|_| (MO) |_|_| (YEAR)

21. What was the result of the **biopsy**? |_|

- (1) Positive
- (2) Negative
- (8) I don't remember
- (9) I don't know

22. What did your doctor say or recommend about the results of the **biopsy**? |_|

- (1) Information provided by the doctor: _____

- (8) I don't remember
- (9) I don't know

23. Has any of your family members ever had breast cancer? |_|

- (1) Yes
- (0) No **GO TO QUESTION #25, PG. 5**
- (8) I don't remember **GO TO QUESTION #25, PG. 5**
- (9) I don't know **GO TO QUESTION #25, PG. 5**

24. Which family member?

INTERVIEWER: FOR EACH FAMILY MEMBER MENTIONED BY THE INTERVIEWEE ASK IF THE PERSON IS ON THE MOTHER'S OR FATHER'S SIDE OF THE FAMILY. MARK ONE (1) IN THE SPACE CORRESPONDING TO THE FAMILY MEMBER MENTIONED BY THE INTERVIEWEE AND ZERO (0) IN THE SPACE FOR MEMBERS NOT MENTIONED.

REMEMBER TO ASK, WHEN APPLICABLE, IF THE FAMILY MEMBER IS BIOLOGICAL (RELATED BY BLOOD)

	MATERNAL SIDE ONLY	PATERNAL SIDE ONLY	FAMILY MEMBER
a. Mother	N/A	N/A	<input type="checkbox"/>
b. Daughter	N/A	N/A	<input type="checkbox"/>
c. Niece	N/A	N/A	<input type="checkbox"/>
d. Granddaughter	N/A	N/A	<input type="checkbox"/>
e. Sister	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> (BY FATHER AND MOTHER)
f. Aunt	<input type="checkbox"/>	<input type="checkbox"/>	N/A
g. Grandmother	<input type="checkbox"/>	<input type="checkbox"/>	N/A
h. Cousin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Other family member _____			
	<i>SPECIFY</i>		
└─→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. Do you have any friends, neighbors or colleagues from work who have been diagnosed with breast cancer or who have died from breast cancer? ☐

(1) Yes → a. What is or was this person's relationship to you? _____

SPECIFY

(WRITE ALL THAT ARE MENTIONED)

(0) No

(8) I don't remember

(9) I don't know

26. Has a doctor ever told you that you have cancer, any type of cancer? ☐

(1) Yes

(0) No *GO TO SECTION C, PG. 6*

(8) I don't remember *GO TO SECTION C, PG. 6*

(9) I don't know *GO TO SECTION C, PG. 6*

27. With what type of cancer were you diagnosed?

(1) Breast cancer

(0) Other type of cancer: _____ **GO TO SECTION C**
SPECIFY

(8) I don't remember **GO TO SECTION C**

(9) I don't know **GO TO SECTION C**

28. When were you diagnosed with breast cancer?

DATE : → **GO TO SECTION C**
(MO.) (YEAR)

INTERVIEWER: IF THE INTERVIEWEE DOES NOT REMEMBER THE
DATE OF THE DIAGNOSIS, GO TO QUESTION #29

29. How old were you when you were diagnosed with breast cancer? → AGE:

C. EARLY DETECTION PRACTICES

THE FOLLOWING QUESTIONS REFER TO PRACTICES RELATING TO YOUR HEALTH.

30. Can you tell me what are the different ways that you know that are used to detect or discover breast cancer in its early stages?

INTERVIEWER: WRITE ONE (1) FOR THE METHODS THAT ARE
MENTIONED BY THE INTERVIEWEE. WRITE ZERO (0) FOR THE
METHODS THAT ARE NOT MENTIONED.

(a) Mammogram (A breast x-ray)

(b) Clinical exam (Breast exam by a doctor or a nurse)

(c) Self-exam (Examining or touching your breasts)

(d) Other _____

SPECIFY

(e) I don't remember

(f) I don't know

31. Has a doctor or a health professional ever explained to you about a mammogram (a breast x-ray)?

(1) Yes

(0) No

(8) I don't remember

(9) I don't know

AS I MENTIONED TO YOU AT THE BEGINNING OF THE INTERVIEW, WE IDENTIFIED POSSIBLE PARTICIPANTS FOR THIS STUDY FROM DIFFERENT HEALTH CENTERS. FROM EACH CENTER, WE OBTAINED A LIST OF THE WOMEN WHO HAVE RECEIVED AT LEAST ONE REFERRAL (ORDER/PRESCRIPTION) FOR A MAMMOGRAM (A BREAST X-RAY) DURING THE PAST TWO YEARS AND THE DATES OF THESE REFERRALS. YOUR NAME IS ON THIS LIST AND THE DATE FOR YOUR LAST REFERRAL WAS:

[SEE PARTICIPANT'S CONTROL CARD]
 (DAY) (MO.) (YEAR)

INTERVIEWER:

→ IF QUESTION #27 PAGE 6 WAS ANSWERED [1] BREAST CANCER, GO TO QUESTION #33 AND REFER TO THE DATE OF THE REFERRAL THAT APPEARS ON THE PARTICIPANT'S CONTROL CARD.

→ IF THE ANSWER TO QUESTION #27 PAGE 6 WAS NOT [1] BREAST CANCER, CONTINUE WITH QUESTION # 32 .

32. After this date, [REPEAT THE DATE OF THE LAST REFERRAL] has any doctor given you another referral (order/prescription) for a mammogram (breast x-ray)?

- (1) Yes
- (0) No **GO TO QUESTION #33**
- (8) I don't remember **GO TO QUESTION #33**
- (9) I don't know **GO TO QUESTION #33**

a. When did the doctor give you this referral? →DATE:
 (DAY) (MO.) (YEAR)

INTERVIEWER: IF THE INTERVIEWEE ANSWERED QUESTION #32-A, WRITE THE DATE ON THE PARTICIPANT'S CONTROL CARD.

33. What type of doctor gave you your last referral (order/prescription) for a mammogram (breast x-ray)? Was the doctor a.

READ ALL OF THE ALTERNATIVES

- (1) Gynecologist/Obstetrician (a doctor who treats women's diseases)?
 **GO TO QUESTION #34, PG. 8**
- (2) General practitioner? **GO TO QUESTION #34, PG. 8**
- (3) Family doctor? **GO TO QUESTION #34, PG. 8**
- (4) Internist? **GO TO QUESTION #34, PG. 8**
- (5) Another type of specialist?

SPECIFY..... GO TO QUESTION #34, PG. 8

- (8) I don't remember
- (9) I don't know

INTERVIEWER: IF THE INTERVIEWEE DOES NOT KNOW THE SPECIALITY OF THE DOCTOR, ASK QUESTION #33 A AND B

a. What is the name of the doctor who gave you the last referral (order/prescription) for a mammogram? **NAME:** _____

b. What is the name of the health center where you saw the doctor who gave you the referral? **CENTER:** _____

34. During the last visit when you received the referral (order/prescription) for a mammogram (breast x-ray) did this doctor. . .

**READ ALL OF THE ALTERNATIVES. MARK (1)=YES; (0)=NO;
(8) =I DON'T REMEMBER; (9)= I DON'T KNOW**

a) . . . talk to you about breast cancer? ☐

b) . . . explain to you about the ways (procedures or methods) to detect (discover) breast cancer in its early stages? ☐

c) . . . show you how to examine your own breasts (self-exam or touch your own breasts)? ☐

d) . . . do an exam of your breasts (when the doctor touches your breasts)? ☐

e) . . . explain the reasons to give you a referral for a mammogram (breast x-ray)? ☐

f) . . . tell you how often you should have a mammogram (breast x-ray)? ☐

35. Thinking about the last referral (order/prescription) for a mammogram (breast x-ray) that your doctor gave you, the referral on (**INTERVIEWER: REPEAT THE DATE OF THE LAST REFERRAL REGISTERED ON THE PARTICIPANT'S CONTROL CARD**), why did the doctor give you this referral (order/prescription)? [**READ ALL OF THE ALTERNATIVES**] ☐

(1) Did you ask for the referral (order/prescription) as a routine check-up?

(2) Did you ask for the referral (order/prescription) because you felt some type of symptom or discomfort?

(3) Did the doctor recommend it as a routine check-up?

(4) Did the doctor recommend it because you had some kind of symptom or discomfort?

(5) Other reason _____

SPECIFY

(8) I don't remember

(9) I don't know

36. Once you received the referral (order/prescription), did you have the mammogram (breast x-ray)? ☐

(1) Yes

(0) No **GO TO QUESTION #38**

(8) I don't remember

(9) I don't know

37. When did you have this mammogram (breast x-ray)?

→ **DATE OF MAMMOGRAM:**
(MO.) (YEAR)

GO TO QUESTION #46, PG. 12

38. What was the **main reason** for **NOT** having the mammogram (breast x-ray) when the doctor gave you the referral (order/prescription)? ☐

(01) I didn't know that I had to have it

(02) I didn't think that it was necessary

(03) I didn't think that it was important

(04) I didn't have any symptoms

(05) I didn't have the money at the time

(06) My health insurance doesn't cover it

(07) It's painful

(08) It's uncomfortable

(09) I didn't have anyone to take care of my children

(10) I had transportation problems

(11) Careless/ Forgetful/ Lazy/ Neglectful

(12) My husband didn't let me go

(13) The clinic's schedule wasn't convenient for me

(14) Afraid of cancer, surgery or dying

(15) I am waiting for an appointment

(16) I didn't know where to go

(17) I didn't have the time

(18) Other reason: _____
SPECIFY

39. Are there any **other reasons** besides this for **NOT** having the mammogram (breast x-ray) when the doctor gave you the referral (order/prescription)? ☐

(1) Yes

(0) No **GO TO QUESTION #41, PG. 10**

40. What are the other reasons for **NOT** having the **mammogram** (breast x-ray) when the doctor gave you the referral (order/prescription)? Was it because. . .

INTERVIEWER: READ ALL OF THE ALTERNATIVES. WRITE ONE (1) FOR ANY REASON MENTIONED BY THE INTERVIEWEE; ZERO (0) FOR ANY REASON NOT MENTIONED; (7) IF IT DOES NOT APPLY. Do NOT READ THE ALTERNATIVE MENTIONED IN QUESTION #38.

- (a) you didn't know that you had to have it? ☐
- (b) you didn't think that it was necessary? ☐
- (c) you didn't think that it was important? ☐
- (d) you didn't have any symptoms? ☐
- (e) you didn't have the money at the time? ☐
- (f) your health insurance doesn't cover it? ☐
- (g) it's painful? ☐
- (h) it's uncomfortable? ☐
- (i) you didn't have anyone to take care of your children/grandchildren or other person who you care for? ☐
- (j) you had problems with transportation? ☐
- (k) careless/ forgetful/ lazy/ neglectful? ☐
- (l) your husband didn't let you go? ☐
- (m) the clinic's schedule wasn't convenient for you? ☐
- (n) you were afraid of cancer, surgery, or dying? ☐
- (o) you are waiting for the appointment? ☐
- (p) you didn't know where to go? ☐
- (q) you didn't have the time? ☐
- (r) Another reason? _____ ☐

SPECIFY

41. Have you ever had a mammogram (breast x-ray)? ☐

- (1) Yes
- (0) No **GO TO QUESTION #43**
- (8) I don't remember **GO TO QUESTION #46, PG. 12**
- (9) I don't know **GO TO QUESTION #46, PG. 12**

42. How long has it been since you had your last mammogram (breast x-ray)?

| |

- (1) One year ago or less
- (2) Two years ago
- (3) Three years ago
- (4) Four years ago
- (5) Five years ago or more
- (8) I don't remember
- (9) I don't know

GO TO QUESTION #46, PG. 12

43. What is your main reason for NEVER having had a mammogram (breast x-ray)?

| | |

- | | |
|--|--|
| (01) I didn't know that I had to have one | (11) Careless/ Forgetful/ Lazy/ Neglectful |
| (02) I don't think that it's necessary | (12) My husband won't let me go |
| (03) I don't think that it's important | (13) The clinic's schedule isn't convenient for me |
| (04) I don't have any symptoms | (14) Afraid of cancer, surgery or dying |
| (05) I don't have the money | (15) I'm waiting for an appointment |
| (06) It's painful | (16) I don't know where to go |
| (07) My health insurance doesn't cover it | (17) I don't have the time |
| (08) It's uncomfortable | (18) Other reason: _____ |
| (09) I don't have anyone to take care of my children | SPECIFY |
| (10) I have problems with transportation | |

44. Are there any other reasons for NEVER having had a mammogram (breast x-ray)?

| |

- (1) Yes
- (0) No **GO TO QUESTION #46, PG. 12**

45. What are the other reasons for NEVER having had a mammogram (breast x-ray) Was it because. . .

INTERVIEWER: READ ALL OF THE ALTERNATIVES. WRITE ONE (1) FOR ANY REASON MENTIONED BY THE INTERVIEWEE; ZERO (0) FOR ANY REASON NOT MENTIONED; (7) IF IT DOES NOT APPLY. DO NOT READ THE ALTERNATIVE MENTIONED IN QUESTION #43.

- (a) you didn't know that you had to have it? ☐
- (b) you don't think that it's necessary? ☐
- (c) you don't think that it's important? ☐
- (d) you don't have any symptoms? ☐
- (e) you don't have the money at this time? ☐
- (f) your health insurance doesn't cover it? ☐
- (g) it's painful? ☐
- (h) it's uncomfortable? ☐
- (i) you don't have anyone to take care of your children/grandchildren or other person who you care for? ☐
- (j) you have problems with transportation? ☐
- (k) careless/ forgetful/ lazy/ neglectful? ☐
- (l) your husband won't let you go? ☐
- (m) the clinic's schedule isn't convenient for you? ☐
- (n) you're afraid of cancer, surgery, or dying? ☐
- (o) you're waiting for the appointment? ☐
- (p) you don't know where to go? ☐
- (q) you don't have the time? ☐
- (r) Other reason? _____ ☐

SPECIFY

46. Do you examine your own breasts (touch your breasts to look for or find masses, bumps, lumps or changes in the skin, a self-exam)? ☐

(1) Yes

(0) No **GO TO QUESTION #48, PG. 13**

47. How often did you examine your breasts during the last _____ (month before)?

a. Number of times

| |

b. This is the number of times

| |

(1) each week

(2) each month

(8) I don't remember

(9) I don't know

INTERVIEWER: MENTION THE PREVIOUS MONTH.

48. Who taught you or how did you learn to examine your breasts (touch your breast or breast self-exam)?

INTERVIEWER: MARK ONE (1) FOR EVERY ALTERNATIVE MENTIONED BY THE INTERVIEWEE AND ZERO (0) FOR ANY ALTERNATIVE NOT MENTIONED.

(a) Doctor

| |

(b) Nurse

| |

(c) Other Health Professional

| |

(d) Educational talks

| |

(e) Informational materials from a health center/hospital/doctor's office

| |

(f) Television / radio

| |

(g) A family member/neighbor/friend

| |

(h) I don't remember

| |

(i) I have never received any information

| |

(j) I do not know how to examine my breasts

| |

(k) Other source _____

| |

SPECIFY

D. PERCEPTION OF DOCTOR-PATIENT RELATIONSHIP

THE FOLLOWING QUESTIONS REFER TO THE TREATMENT THAT YOU RECEIVE FROM THE MAJORITY OF THE DOCTORS YOU HAVE VISITED. FOR EACH QUESTION, ANSWER IF YOU HAVE NEVER FELT THIS WAY, SOMETIMES, ALMOST ALWAYS OR ALWAYS FELT THIS WAY.

INTERVIEWER: READ ALL OF THE ALTERNATIVES. FOR QUESTIONS 49-54, CIRCLE THE NUMBER OF THE ALTERNATIVE THAT CORRESPONDS TO THE INTERVIEWEE'S ANSWER. EMPHASIZE THAT THE QUESTIONS REFER TO THE MAJORITY OF THE DOCTORS THAT THE INTERVIEWEE HAS VISITED.

49. Do you feel that the majority of the doctors you have visited:

	NEVER	SOMETIMES	ALMOST ALWAYS	ALWAYS
(a) listen to what you tell them about how you feel?	1	2	3	4
(b) answer the questions that you might have about your health or about any treatment or medicine that they prescribe?	1	2	3	4
(c) pay enough attention to you?	1	2	3	4

Do you feel that the majority of the doctors you have visited:

(d) are concerned about your health?	1	2	3	4
(e) give you information about the results from the tests that they sent you to have?	1	2	3	4
(f) keep you up-to-date with information about your health?	1	2	3	4
(g) are attentive to you?	1	2	3	4

FOR THE FOLLOWING QUESTIONS, PLEASE TELL ME IF YOU FEEL NOT AT ALL SATISFIED, SOMEWHAT SATISFIED, SATISFIED OR VERY SATISFIED. REMEMBER, WE ARE ASKING ABOUT THE TREATMENT THAT YOU RECEIVE FROM THE MAJORITY OF THE DOCTORS YOU HAVE VISITED.

INTERVIEWER: READ ALL OF THE ALTERNATIVES	NOT AT ALL	SOMEWHAT	SATISFIED	VERY
	SATISFIED	SATISFIED		SATISFIED
50. How satisfied are you with the way <u>the majority</u> of the doctors tell you things?	1	2	3	4
51. How satisfied are you with the way <u>the majority</u> of the doctors treat you?	1	2	3	4

E. ATTITUDE ABOUT HEALTH

NEXT WE ARE PRESENTING VARIOUS STATEMENTS RELATING TO YOUR HEALTH. PLEASE TELL US IF YOU AGREE OR DISAGREE.

INTERVIEWER: READ ALL ALTERNATIVES.	AGREE	DISAGREE	I DON'T KNOW
52. If your doctor prescribes you a medicine, you take it even though it affects your daily life	1	2	9
53. If you take care of yourself, you can prevent dying from breast cancer.	1	2	9
54. You visit the doctor even if you don't feel sick.	1	2	9

F. KNOWLEDGE ABOUT BREAST CANCER

YOUR OPINION IS VERY IMPORTANT FOR US TO LEARN ABOUT WHAT WOMEN IN PUERTO RICO THINK ABOUT BREAST CANCER. NEXT I AM GOING TO READ YOU VARIOUS STATEMENTS ABOUT BREAST CANCER AND I WOULD LIKE TO KNOW YOUR OPINION. WHEN I READ A SENTENCE, PLEASE TELL ME IF YOU THINK THAT THE STATEMENT IS TRUE OR FALSE.

INTERVIEWER: MARK AN (X) FOR THE RESPONSE IN THE CORRESPONDING COLUMN. IF THE INTERVIEWEE ANSWERS "I DON'T KNOW", DOES NOT ANSWER, OR APPEARS TO NOT UNDERSTAND THE SENTENCE, READ IT AGAIN AND REPEAT "YOUR OPINION IS VERY IMPORTANT TO US". DO NOT CHANGE THE WORDS IN THE SENTENCE.

STATEMENTS	TRUE	FALSE	I DON'T KNOW
55. A possible symptom of breast cancer is liquid coming out of the nipple.			
56. A lump (hardening, nodule, bump, mass) in the breast is a symptom of breast cancer.			
57. Women who don't have children have less chance of having breast cancer.			
58. Women age 40 and over should have a mammogram (breast x-ray) every year.			
59. Hitting, bruising or injuring the breast can cause breast cancer.			
60. When a mother or sister has had breast cancer, a women has a greater possibility of developing this cancer.			
61. Breast cancer is always painful.			
62. Pain, burning or discomfort in the breast or nipple are possible symptoms of breast cancer.			
63. A mammogram (breast x-ray) detects (discovers) breast cancer in its early stages.			
64. Women under the age of 50 have more chance of developing breast cancer than women over this age.			
65. A mammogram (breast x-ray) is only necessary when a woman feels discomfort in her breasts.			
66. Women who smoke have a greater risk of developing breast cancer.			
67. Women who have children before age 30 have a greater risk of developing breast cancer.			
68. Women on low-fat diets have a greater possibility of developing breast cancer.			
69. Breast cancer always results in death.			
70. A mammogram (breast x-ray) is the most accurate or efficient test for detecting (discovering) breast cancer.			
71. Women who breast-feed their children have a greater possibility of developing breast cancer.			

G. SOURCES OF INFORMATION

THE FOLLOWING QUESTIONS REFER TO THE DIFFERENT WAYS THAT YOU RECEIVE INFORMATION ABOUT BREAST CANCER.

72. Where or from whom have you received information about breast cancer?

INTERVIEWER: MARK ONE (1) FOR EACH ALTERNATIVE THAT THE INTERVIEWEE MENTIONS AND ZERO (0) FOR THE ALTERNATIVES NOT MENTIONED.

- (a) Doctor ☐
- (b) Nurse ☐
- (c) Health professionals ☐
- (d) Radio ☐
- (e) Television ☐
- (f) Reading materials (newspapers, magazines, books) ☐
- (g) Family members ☐
- (h) Friends / Neighbors ☐
- (i) Informative materials in health centers ☐
- (j) Other sources _____ ☐
SPECIFY

73. Where or from whom did you receive information about mammograms (breast x-rays)?

INTERVIEWER: MARK ONE (1) FOR EACH ALTERNATIVE THAT THE INTERVIEWEE MENTIONS AND ZERO (0) FOR THE ALTERNATIVES NOT MENTIONED.

- (a) Doctor ☐
- (b) Nurse ☐
- (c) Health professionals ☐
- (d) Radio ☐
- (e) Television ☐
- (f) Reading materials (newspapers, magazines, books) ☐
- (g) Family members ☐
- (h) Friends / Neighbors ☐
- (i) Informative materials in health centers ☐
- (j) Other sources _____ ☐
SPECIFY

H. ACCESS TO SERVICES

THE FOLLOWING QUESTIONS ARE RELATED TO MEDICAL APPOINTMENTS.

74. The majority of time, what transportation do you use to get to your medical appointments? ☐

- (1) Own car
- (2) Public transportation (bus or public van)
- (3) Family member's car
- (4) Neighbor or friend's car
- (5) I pay someone to take me
- (6) Municipality or government transportation
- (7) Private transportation
- (8) Walk
- (9) Other means of transportation _____

SPECIFY

75. The majority of the time, who goes with you to the doctor's office when you have an appointment? ☐

- (0) No one
- (1) My husband (spouse)
- (2) My daughter(s)
- (3) My son(s)
- (4) My daughter-in-law or son-in-law
- (5) My sister(s) or brother(s)
- (6) Another family member
- (7) My friend(s) /neighbor(s)
- (8) Another person _____

SPECIFY

76. If you take care of small children, grandchildren or another person, do you have any problems finding someone to take care of her/him/them when you have a doctor's appointment? ☐

- (1) Never
- (2) Sometimes
- (3) Almost always
- (4) Always
- (5) I don't take care of anyone **GO TO QUESTION #77, Pg. 19**

a. Who do you take care of? ☐

- (1) Small children or grandchildren
- (2) Live-in partner
- (3) Mother
- (4) Father
- (5) Other family member _____

SPECIFY

I. STATE OF HEALTH

THE FOLLOWING QUESTIONS REFER TO YOUR CURRENT STATE OF HEALTH.

77. Have you visited a doctor (any type of doctor) in the last twelve months? |_|

(1) Yes

(0) No **GO TO QUESTION #79, PG. 19**

(8) I don't remember **GO TO QUESTION #79, PG. 19**

(9) I don't know **GO TO QUESTION #79, PG. 19**

78. How often have you visited the doctor (any type of doctor) in the last twelve months, that is from (Month, 1999) through (Month, 2000). |_|_|

a. Number of times |_|

b. This number of times is [READ THE ALTERNATIVES]

(1) each week

(2) each month

(3) each year

(8) I don't remember

(9) I don't know

79. Have you been diagnosed with any of the following conditions?

**INTERVIEWER: READ ALL OF THE ALTERNATIVES.
CIRCLE THE NUMBER THAT CORRESPONDS TO THE
INTERVIEWEE'S ANSWER.**

	YES	NO	I DON'T REMEMBER	I DON'T KNOW
(a) Diabetes	1	0	8	9
(b) High blood pressure	1	0	8	9
(c) Asthma	1	0	8	9
(d) Heart diseases	1	0	8	9
(e) High cholesterol	1	0	8	9
(f) Thyroid problems	1	0	8	9
(g) Arthritis	1	0	8	9
(h) Nervous diseases (emotional)	1	0	8	9
(i) Migraine headaches	1	0	8	9
(j) Vaginal bleeding	1	0	8	9
(k) Other _____	1	0	8	9

SPECIFY

80. For the age that you have. How do you rate your health?
[READ ALTERNATIVES]

- (1) Good
- (2) Regular
- (3) Bad

J. KNOWLEDGE ABOUT EXISTING SERVICES

NOW WE ARE GOING TO ASK A FEW QUESTIONS ABOUT THE PLACES WHERE MAMMOGRAMS ARE DONE.

81. Do you know of any places where mammograms (breast x-rays) are done?

(1) Yes (a) Name at least one place: _____

(0) No ***GO TO SECTION K***

82. Do you know any places where you can go to have a mammogram (breast x-ray)?

(1) Yes (a) Name at least one place: _____

(0) No

K. SOCIOECONOMIC INFORMATION

THIS IS THE LAST SECTION OF THE INTERVIEW. THESE QUESTIONS REFER TO YOUR HOME.

83. How many people live in your home?

INTERVIEWER: IF THE INTERVIEWEE LIVES ALONE, WRITE ONE (01) AND GO TO QUESTION # 85.

84. Who do you live with?

INTERVIEWER: READ ALL OF THE ALTERNATIVES. WRITE ONE (1) FOR EACH ALTERNATIVE MENTIONED BY THE INTERVIEWEE. WRITE ZERO (0) IF AN ALTERNATIVE IS NOT MENTIONED.

- (a) Husband (Spouse/Partner) ☐
- (b) Daughter(s) ☐
- (c) Son(s) ☐
- (d) Grandchild (Grandchildren) ☐
- (e) Sister(s) or Brother(s) ☐
- (f) Other family member ☐
- (g) Friend(s) ☐
- (h) Other person _____ ☐

SPECIFY

85. What are your household's sources of income?

INTERVIEWER: READ ALL OF THE ALTERNATIVES. WRITE ONE (1) FOR ALL OF THE SOURCES MENTIONED BY THE INTERVIEWEE. WRITE ZERO (0) FOR ANY ALTERNATIVE NOT MENTIONED.

- (a) My own salary ☐
- (b) My husband's salary ☐
- (c) Economic Assistance Programs (Welfare) ☐
- (d) Nutritional Assistance Programs (food stamps, work/food stamps) ☐
- (e) Social Security ☐
- (f) Retirement Pension ☐
- (g) Financial assistance from child (children) ☐
- (h) Financial assistance from parents ☐
- (i) Rent from properties or house ☐
- (j) Own business ☐
- (k) Child support for one or more children ☐
- (l) Other sources _____ ☐

SPECIFY

**THAT WAS THE LAST QUESTION. WE THANK YOU VERY MUCH FOR YOUR
COOPERATION AND YOUR TIME TO RESPOND TO THESE QUESTIONS.
THANK YOU VERY MUCH!**

REMINDER TO INTERVIEWER

CHECK THAT YOU HAVE THE FOLLOWING DOCUMENTS:

- ✓ **SIGNED CONSENT FORM**
- ✓ **SIGNED RECEIPT FOR APPRECIATION GIFT**
- ✓ **IDENTIFIED QUESTIONNAIRE**

**THANK THE PARTICIPANT AGAIN
FOR HER COOPERATION AND ASSISTANCE!**

